

Governor's Commission on Home and Community-Based Services



Fact Book

April 24, 2003

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INTRODUCTION

The Commission on Home and Community Based Services exists to pursue common and aggressive actions that will facilitate immediate and lasting change in long term care services in Indiana. The Commission's work is targeted to persons who already are, or who may sometime in the future depend upon long-term care services. The Commission will develop recommended actions based upon a public policy that makes sense, is financially accountable and promotes personal choice by the persons receiving, or at risk of receiving, these services. The Commission will build upon the good work already accomplished by other commissions and groups and will be guided by activities and implementation strategies that improve the lives of people currently affected by these services. Each recommended action is intended to help overcome the well-known systemic barriers, current policies and procedures, and organizational practices that are obstacles to change.

ACKNOWLEDGMENTS

This report represents the culmination of several months of conceptualizing, data collection, and analysis. It could not have happened without the leadership of Katie Humphreys, and the support of Elizabeth Galvin, Katie Howard, Richard Deliberty, Tammy Robinson, Celia Leaird, Seth Frotman (Indiana University Law Student), Roger Sell, Wanda Williams and the dedicated staff of the Family and Social Services Administration and Health Evolutions. We hope that the report contributes to policy decisions that will improve the lives and opportunities of those receiving, or at risk of receiving, long term care services in Indiana.

SECTION I: THE POPULATIONS

Indiana's population by age group as compared to the United States population by age is demonstrated below. Additionally, 9.5% of Indiana's population lives at or below poverty as compared with 12.4% of the USA population.

Population Facts

	Indiana	USA
Population, 2001 estimate	6,114,745	284,796,887
Population, 2000	6,080,485	281,421,906
Population, percent change, 1990 to 2000	9.7%	13.1%
Persons under 5 years old, percent, 2000	7.0%	6.8%
Persons under 18 years old, percent, 2000	25.9%	25.7%
Persons 65 years old and over, percent, 2000	12.4%	12.4%
Persons over 18 years old and under 65	54.7%	55.1%

Source: iii

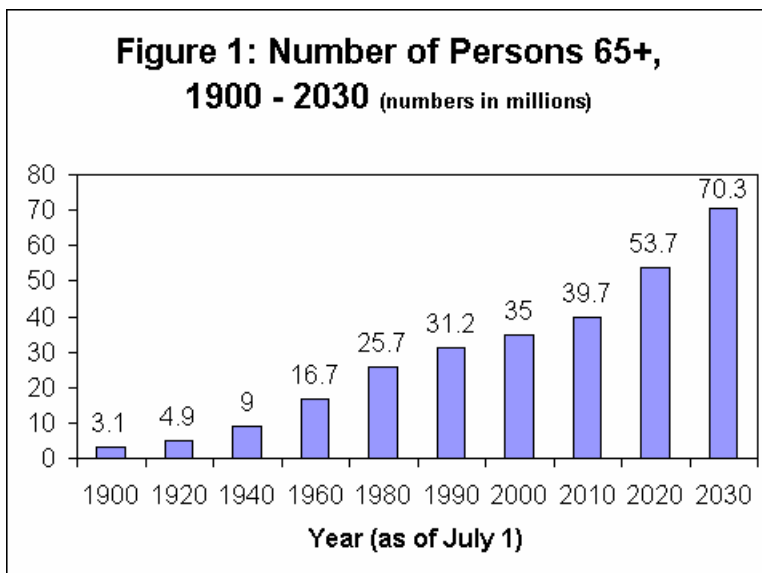
What Populations have the Task Forces Reviewed?

The Task Forces have looked at demographics and services for

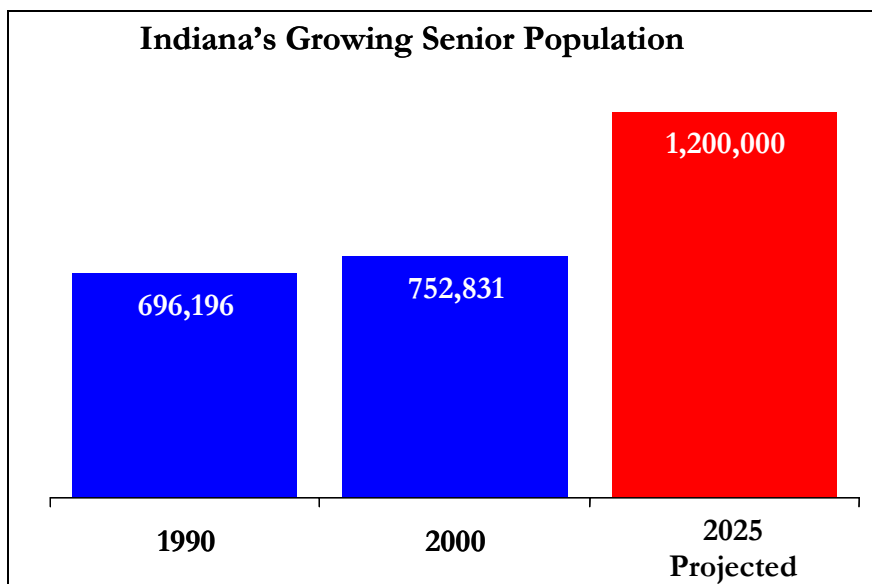
- The elderly (age 65 and older)
- Persons with Developmental Disabilities
- Persons with mental illness
- Persons with physical disabilities
- Children who are at-risk

1. **The Elderly**

"Seniors" are defined as persons who are age 65 or older. This segment of the population is growing rapidly. The 2000 U.S. Census counted 35 million people who are age 65 or older in the United States, a 12% increase in the senior population since 1990. It is predicted that this number will double by 2030, to about 70 million seniors. Seniors will then represent 20% of the American population, up from 12.4% in the year 2000. In addition, the percentage of seniors nationwide with disabilities is expected to increase 27%, from 6.2 million in 2000 to 7.9 million in 2020.



In Indiana, 12.4% of the population was 65 or older in 2000.ⁱ This translates to more than 752,000 persons, or one in every eight Hoosiers. According to data compiled by the Federal Administration on Aging, there was an 8.1% increase in the number of persons age 65 and older in Indianaⁱⁱ from 1990 to 2000. By 2025, Indiana's 65 and older population is expected to increase to over 1.2 million, making it the second-largest age group in the state, and 19.2% of Hoosiers. This represents a 59.57% increase.



- **How many seniors are in need of care?**

Within this population group, it is estimated that at least 60 percent of people 75 and older will require some type of long term care over their remaining lifetime. In 2001, there were 40,000 Hoosier seniors in nursing homes. Medicaid paid for 2 out of 3 nursing home beds (\$813 million). Although Indiana had a very high nursing home bed ratio per 1,000 people, age 65 and older in 1999 (83.8 beds compared to a national average of 52.3 beds), expenditures for nursing facilities experienced a 2.4% decrease from 1995 to 2000.

Of Medicaid long-term care recipients, 73.5% received care (in 2000) in either a nursing home, ICF/MR, or group home, while 7.1% received their long-term services through Medicaid waiver programs.

Medicare Enrollment *

As of July 1, 2001

	Total Population	Medicare -- All Beneficiaries		Disabled Beneficiaries		Aged Beneficiaries	
		Enrolled	%	Enrolled	%	Enrolled	%
United States	284,796,887	39,149,152	13.7%	5,405,700	1.9%	33,743,452	11.8%
Indiana	6,114,745	858,150	14.0%	120,335	2.0%	737,815	12.1%

* Enrollment is defined here as having coverage through Hospital Insurance and/or Supplemental Medical Insurance.

- **How many seniors are below the Federal Poverty Limit?**

The federal poverty guidelines are calculated according to the following guidelines:

2002 HHS Poverty Guidelines	
Size of Family Unit	Contiguous States and D.C.
1	\$8,860
2	11,940
3	15,020
4	18,100
5	21,180
6	24,260
7	27,340
8	34,420
<i>For each additional person, add \$3,080</i>	

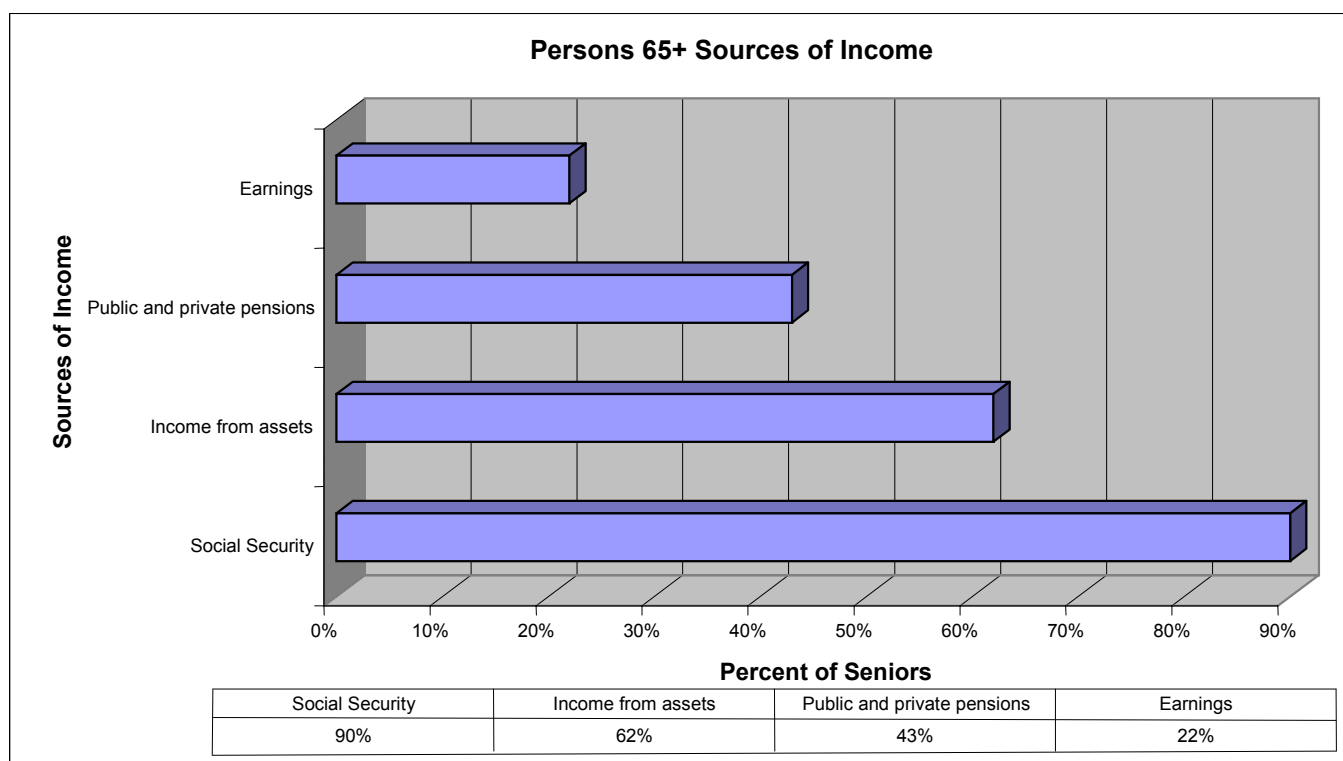
About 3.4 million elderly persons (10.1%) were below the poverty level nationally in 2001. These figures remained relatively constant from the historic low reached in 1999. Another 2.2 million or 6.5% of the elderly were classified as "near-poor" with an income between the poverty level and 125% of this level.

According to data compiled by the Federal Administration on Aging, calculated on the basis of the official poverty definitions for the years 1999-2001, 7.8 percent of Indiana seniors aged 65 and older are below the federal poverty level.ⁱⁱⁱ This is somewhat lower than the national average of 9.9 percent. Approximately 70,000 Hoosier seniors have monthly incomes less than \$738 and annual incomes less than \$8,860.

- **What is the major source of income for seniors?**

The Social Service Administration reported that the major sources of income for seniors in 2000 were the following:

- Social Security
- Income from assets
- Public and private pensions
- Earnings^{iv}



2. **Adults and Children with Developmental Disabilities**

• **Who are the Adults and Children with Developmental Disabilities?**

Developmental disabilities are severe, chronic disabilities attributable to mental and/or physical impairment (other than the sole diagnosis of mental illness), which manifest before age 22 and are likely to continue indefinitely. They result in substantial limitations in three or more of the following areas:

- Self-care
- Receptive and expressive language
- Learning
- Mobility
- Self-direction
- Capacity for independent living
- Economic self-sufficiency

There are nearly four million Americans with developmental disabilities nationwide. Approximately 3 percent (182,000) of Indiana's population have a developmental disability.^v Indiana has 1,800 people with Developmental Disabilities in nursing homes. Only four states have more.

In SFY 2000, of Indiana's 23,431 enrollees with developmental disabilities and mental retardation, 2.2 were served in state operated facilities, 4.0 percent receive care in ICFs/MR, and 16.1 percent in group homes. The number of facility residents declined approximately 50% in SFY 2000.

The numbers of MR/DD individuals currently receiving services identified by program areas are:

Service Setting	Clients	% of Total
Nursing Homes	4,396	33.5%
Group Homes	3,795	29.0%
Individuals on Individual Community Living Budgets (100% State funds)	3,315	25.3%
Large, Private ICFs/MR (11 Facilities)	832	6.3%
State Developmental Centers	608	4.6%
State Hospitals	160	1.2%
	13,106	100.0%

3. **Adults and Children Who Are Mentally Ill**

• **Who are the Adults and Children who have mental illness?**

Mental illness is defined as those 18 years of age or older with a diagnosis of a major mental illness, severe disability, and no required duration (including those who have intermittent periods of serious mental illness over a long period of time).

Serious emotional disturbance is defined as those under 18 years of age with a condition that results in improper behavior that interferes with the individual's ability to learn and function under normal circumstances. Children and adolescents with SED have mental health problems that severely disrupt daily life at home, at school, and in the community.

People with serious mental illnesses have to overcome very high hurdles when it comes to entering into the workforce. Some have education gaps, face problems with concentration or endurance, or have medication side effects that make working difficult. There is a very high level of unemployment among persons with mental illness, sometimes as high as 85%.^{vi}

Forty-four million Americans, approximately 13.7 million of those who are children, experience a mental disorder each year.^{vii} One in every five families is affected in their lifetime by a severe mental illness, such as bipolar disorder, schizophrenia and major depression. One in five American children and adolescents may have a behavioral, emotional, or mental health problem. One in ten children and adolescents have mental illnesses severe enough to cause some level of impairment. Yet fewer than one in five of these young people receive needed treatment.^{viii}

In Indiana, an estimated 270,000 adults suffer from mental illness.^{ix} This is approximately 6% of the adult population. An additional 80,000 Hoosier children, ages 9 to 17, suffer from serious emotional disturbances. It is estimated that 223,000 Hoosiers have at least one co-occurring mental health and substance abuse disorder. The data also indicates that the severity of emotional and behavioral problems among adolescents is associated with increased likelihood of substance abuse.^x

4. Adults and Children with Physical Disabilities

The data regarding populations with disabilities is more limited than for other groups. As reflected in the following excerpts of a 1995 Department of Health & Human Services study^{xi}, there are several reasons for the lack of good data:

While much is known about the frail elderly and their use of services, relatively little is known about other groups of persons with disabilities such as children, working age adults and special populations (e.g., mentally ill, developmentally disabled) that cut across age groups.

Numerous Federal surveys collect disability data on the working age population (aged 18-64), but except for the 1994/95 Disability Survey, none focus primarily on disability. That was not always the case. SSA conducted the Surveys of Disability and Work every few years beginning in the early 1960s in order to measure the extent of disability in the working age population and to examine the experience of disabled workers on SSDI and their families. The last Survey of Disability and Work was conducted in 1978 and there are no plans to repeat the survey. Nowadays, data sources include either special surveys on disability (like the 1994/95 Disability Survey) or the addition of disability questions on non-disability surveys.

There are crucial but unresolved definitional and measurement issues among the working age population. No equivalent severity measures and survey questions have been developed for physical versus mental impairments. The standard functioning questions based on ADLs and IADLs often break down.

A small but important segment of the working age population with disabilities are institutionalized (i.e., nursing homes, mental hospitals, prisons) or are homeless. Since few national surveys include this population and since the few surveys which focus on the institutionalized (i.e., the National Nursing Home Survey) have very small samples of the non-elderly, we know little about this group.

Disability Status of the Civilian Non-Institutional Population

	Indiana		U.S.	
	Number	%	Number	%
Population 5 years and over	5,563,619		257,167,527	
With a disability	1,054,757	19.0%	49,746,248	19.3%
Population 5 to 15 years	972,185		45,133,667	
With a disability	61,622	6.3%	2,614,919	5.8%
Sensory	9,746	1.0%	442,894	1.0%
Physical	9,891	1.0%	455,461	1.0%
Mental	50,918	5.2%	2,078,502	4.6%
Self-care	8,306	0.9%	419,018	0.9%
Population 16 to 64 years	3,884,065		178,687,234	
With a disability	691,505	17.8%	33,153,211	18.6%
Sensory	97,418	2.5%	4,123,902	2.3%
Physical	243,669	6.3%	11,150,365	6.2%
Mental	144,016	3.7%	6,764,439	3.8%
Self-care	63,617	1.6%	3,149,875	1.8%
Going outside the home	204,264	5.3%	11,414,508	6.4%
Employment disability	439,868	11.3%	21,287,570	11.9%
Population 65 years and over	707,369		33,346,626	
With a disability	301,630	42.6%	13,978,118	41.9%
Sensory	105,274	14.9%	4,738,479	14.2%
Physical	209,251	29.6%	9,545,680	28.6%
Mental	70,735	10.0%	3,592,912	10.8%
Self-care	64,661	9.1%	3,183,840	9.5%
Going outside the home	138,302	19.6%	6,795,517	20.4%
Population 18 to 34 years	1,419,258		64,654,308	
With a disability	191,349	13.5%	9,468,241	14.6%
Percent enrolled in college or graduate school		12.8%		14.5%
Percent not enrolled and with a bachelor's degree or higher		6.0%		7.9%
No disability	1,227,909	86.5%	55,186,067	85.4%
Percent enrolled in college or graduate school		21.0%		21.4%
Percent not enrolled and with a bachelor's degree or higher		14.4%		17.5%
Population 21 to 64 years	3,434,336		159,131,544	
With a disability	635,620	18.5%	30,553,796	19.2%
Percent employed		60.8%		56.6%
No disability	2,798,716	81.5%	128,577,748	80.8%
Percent employed		80.2%		77.2%

Source: U.S. Census Bureau, Census 2000 Summary File 3, Matrices P42, PCT26, PCT27, PCT28, PCT29, PCT30, PCT31, PCT32, and PCT33.

5. **Children At-Risk**

• **Who are Children At-Risk?**

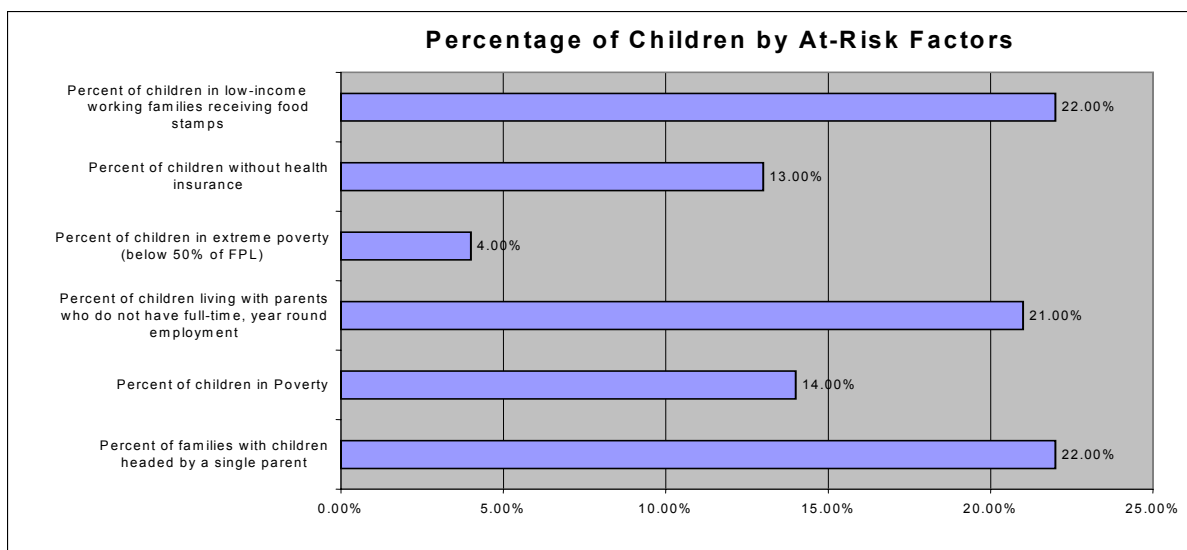
Approximately 26% (1.58 million) of Indiana's population are children 17 and younger.^{xii} The Annie E. Casey Foundation defines the "at risk child" as a child who live in a family with four or more of the following risk factors:^{xiii}

- The child does not live with two parents;
- The head of household is a high school dropout;
- The family income is below poverty level;
- The child lives with underemployed parent(s);
- The family receives welfare benefits;
- The child does not have health insurance.

Census data indicates that 11% (174,000) of Hoosier children live in poverty, compared with 16 % nationally.

In 2000, 12% of children nationally could be classified as at-risk, a decrease of 1% from 1990. The table below reflects the occurrence of risk factors for children in the U.S.

According to data collected by the Annie E. Casey Foundation, 6% (95,000) of Hoosier children are at-risk.^{xiv} Indiana decreased their number of at-risk children by half (12%-6%), marking the second largest improvement of any state between 1990-2000.



SECTION II: SERVICES

This section seeks to define the services vital to the populations described in Section I. National and state data is included where possible.

1. Housing

Of the 21.8 million households headed by older persons in 2001, 80% were owners and 20% were renters. The median family income of older homeowners was \$23,409 and \$12,233 for older renters. In 2001, 41% of older householders spent more than one-fourth of their income on housing costs, compared to 39% of for homeowners of all ages.

Nationally, there are 6.1 million very low- and extremely low-income seniors with priority housing problems. It would take over 40,000 additional housing units a year just to maintain the current ratio of six seniors with unmet housing needs to each subsidized unit now occupied by a senior. It is estimated that there will be 9.5 million low- and extremely low-income seniors in 2020. Assuming that only one-quarter of those seniors want to live in rent-assisted housing it would be necessary to provide 140,000 units a year for the next 17 years.^{xv}

According to the 2000 US Census there are more than 2.5 million housing units in Indiana. There are about 196,000 vacant housing units. Seventy-one percent of the housing units are owner-occupied. Affordable housing is an essential component of family and personal well-being, but locating affordable housing may be easier said than done for a large part of Indiana's special populations. Over 28% of renters pay 35% or more of their income in rent. In Indiana a full-time worker must earn \$10.93 per hour to rent a modest two-bedroom home.

2. Transportation

The inability to access affordable, reliable, and convenient transportation contributes to job loss and low job retention.^{xvi} However, accessible transportation also impacts several other quality of life indicators such as political participation, access to entertainment, socializing, and religious attendance. Likewise, inaccessible transportation negatively impacts the opportunities that all Hoosier families have to not only participate in these vital civic activities, but also to become and maintain self-sufficiency.

For elderly and disabled individuals, the lack of convenient transportation can exacerbate this isolation, as well as negatively impact their ability to work, access health care, groceries, and other essential services. Medicaid eligible individuals can access transportation through their health care benefits for Medicaid eligible services only.

In the year 2000, inaccessibility and unavailability of transportation remains an obstacle that confronts people with disabilities in getting to work and socializing outside the home. Three out of 10 people with a disability have a problem accessing adequate transportation. By contrast, only 1 out of 10 people without disabilities have a problem with inadequate transportation, with only 4% citing it as a major problem. The transportation gap between people with disabilities and people without disabilities has actually widened by 7 percentage points since 1998.^{xvii}

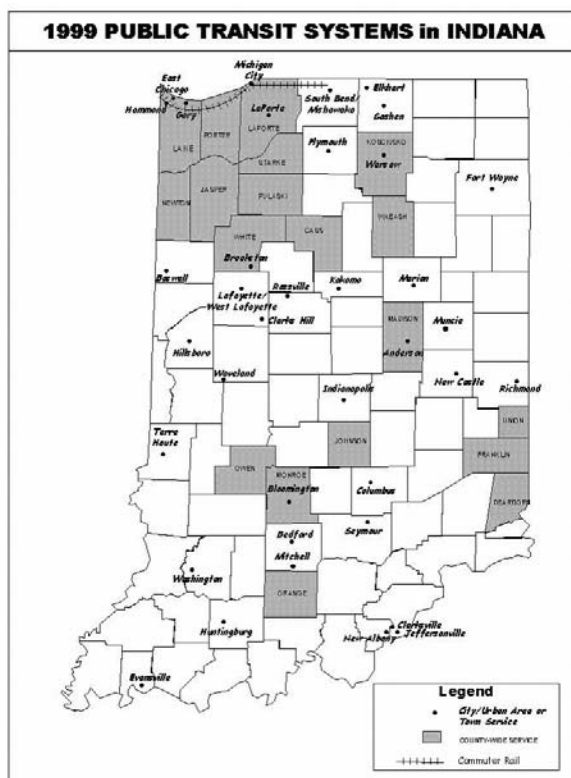
Not surprisingly, inadequate transportation is an even greater obstacle for people with severe disabilities. People with somewhat or very severe disabilities are more than three times as

likely to think transportation is a problem (34% and 36% respectively) than people without disabilities (10%) and twice as likely as people with slight disabilities (17%).^{xvii}

Income also seems to play a large role as people with annual household incomes of \$15,000 or less, whether with disabilities or without disabilities are much more likely to say transportation is a problem than people with annual household incomes of \$50,000 or more.

xvii

Although Indiana has 44 public transit systems, there are 29 counties with no public transportation available. **xvii**



3. Vocational Services

People with disabilities are employed at lower rates than the general population. Moreover, the more severe the disability, the less likely a person is to be employed. The National Organization on Disability reports that only 32% of Americans with disabilities aged 18 to 64 are working, compared to 81% of those without disabilities in this age category.^{xviii} Two-thirds would rather be working.

Of those who said that they had encountered barriers, the majority indicated either that they could not afford training and education programs (35%) or that they were denied entrance into the programs (35%). Only a small minority (9%) replied that they faced discriminatory attitudes on the part of training staff.^{xix}

According to Census 2000 more than 140,000 Indiana civilian non-institutionalized persons age 16 to 64 had an employment disability and were unemployed.^{xx}

4. Community and Personal Assistance Support Services

The populations addressed within this data book obtain their health and personal assistance support services predominately through Medicaid funded programs. The eligibility requirements for Medicaid sponsored programs are:

Members of Families with Children. Families meeting the income and resource standards for the Temporary Assistance to Needy Families (TANF) program are also eligible for Medicaid whether or not they actually receive TANF cash assistance.

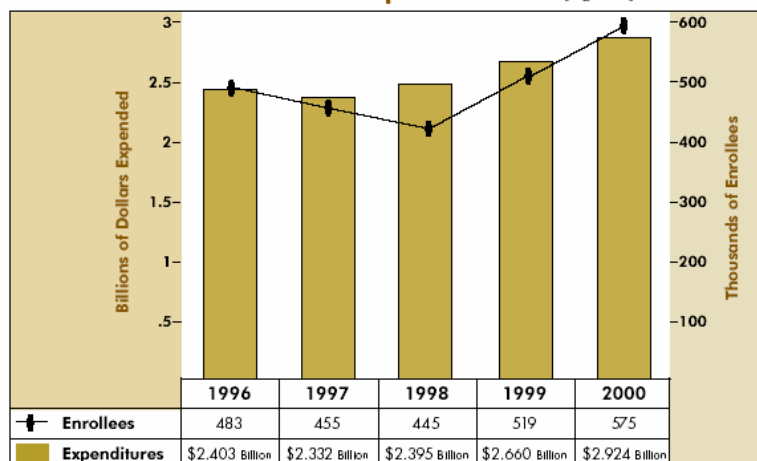
Children and Pregnant Women Pregnant women and children under age nineteen with family incomes up to 150% of the federal poverty level are eligible for Medicaid. Prior to July 1, 1998, children from age one through age five were not eligible if their family incomes exceeded 133% of the federal poverty level and children aged 6 through 18 were not eligible if their family incomes exceeded 100% of the federal poverty level. The income standard and continuous coverage were adopted by the Indiana General Assembly in Public law 58-1998 which is "Phase I" of Indiana's implementation of the federal Children's Health Insurance Program.

Aged. Individuals aged sixty-five or older are eligible for Medicaid if they meet certain financial criteria. The financial criteria are more lenient if one spouse is in a nursing facility, while the other lives in the community. In addition, persons eligible for Medicare Part A may qualify to have Medicaid pay their Medicare premiums, co-payments and deductibles as a Qualified Medicare Beneficiary (QMB), a Qualifying Individual (QI), a Qualified Disabled and Working Individual, or a Specified Low Income Medicare Beneficiary (SLMB).

Blind and Disabled. The definition of "blind" for eligibility purposes is the same as the definition used by the federal Social Security Administration. To be eligible in the disability category, a disabled person must have a physical or mental impairment, disease or loss that appears reasonably certain to continue throughout four or more years of the individual's life without significant improvement and that substantially impairs his/her ability to perform labor or to engage in a useful occupation. Blind and disabled recipients may also be eligible for the Medicare-related programs described above, if they are eligible for Medicare.

The Medicaid program has grown substantially on a national and state level. The growth of the Indiana's Medicaid program is reflected in the increase in enrollees and expenditures:

Medicaid Enrollees and Expenditures^{7,8,9} [Figure 1]

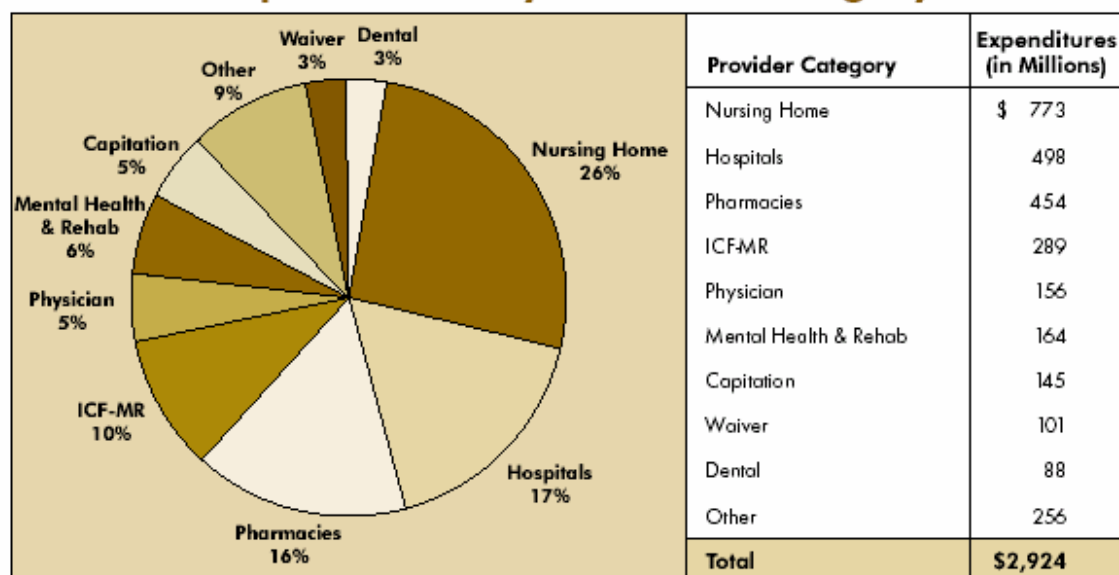


The increase in expenditures is closely related to the growth in services provided in institutional settings such as nursing homes and hospital. This trend is directly related to the growth of the age eighty-five plus population.

Although adults and children in low-income families make up approximately three-quarters of all beneficiaries, the age, blind, and disabled account for 68.8% of State Fiscal Year 2001 spending. Payments by aid group for SFY 2001 are indicated below.

Aid Group	Total Payments	% of Total Payments
Disabled	\$1,210,316,030	37.2%
Aged	\$1,000,948,966	30.8%
Child	\$577,352,418	17.7%
Adult	\$206,437,412	6.3%
Pregnant Women	\$90,301,047	2.8%
CHIP I	\$75,775,573	2.3%
Uncategorized	\$58,389,807	1.8%
Blind	\$26,019,796	0.8%
CHIP II	\$7,565,864	0.2%
Total	\$3,253,106,913	100.0%

Medicaid Expenditures by Provider Category [Figure 2]



Many older and disabled adults have traditionally lived in nursing homes and state run institutions simply because no other alternatives are available to them. Consumer preferences, the high cost of institutional care, and recent Supreme Court rulings (*L.C. & E.W. vs. Olmstead*) have slowly eroded such care-restrictions. In an effort to assist seniors and persons with disabilities in maintaining their independence and privacy, several in-home and community-based personal assistance support services have been incorporate as alternatives to institutionalization.

Community-based care originated as an outgrowth of the idea of meeting the needs of people with disabilities by emphasizing a presence in the community, health and safety, and self-determination. These programs provide high quality, cost effective, and accessible services that afford older persons and persons with disabilities the ability to maintain their independence and privacy by preserving the option to live independently in their own homes as long as possible. In-home services include home health services, homemaker services, attendant care, respite care, adult day services, transportation, home delivered meals, habilitation, therapies and other appropriate services such as minor home modifications and adaptive aids. All of these services are available, including Medicaid waivers, through a case management driven system.

There are more than 291,000 Hoosiers over age 65 who experience some limitation in two or more "activities in daily living" such as bathing, dressing, or walking, and an additional 559,000 Hoosiers below age 65 who experience some limitations in these activities.^{xxi}

5. Institutional Services vs. Community Services

The number of Hoosiers with disabilities and mental illnesses that are receiving services in their home or in their community has more than doubled while the number in institutions has been cut in half.

Although the predominate focus of community-based services rests on maximizing the recipients quality of life, there is no dispute that the cost of institutional care is higher than the cost of services providing in community-based settings. One nationwide study calculated the cost of institutional care as more than six times the average cost of community-based care.

Indiana Nursing Home Facts

Average Medicaid Daily Rate	\$102.08
Average Private Pay Daily Rate	\$120.58
Number of Medicare Certified Beds	3,258
Number of Medicaid Certified Beds	14,421
Number of Dual Medicare/Medicaid Certified Beds	37,786
Number of Medicaid Home Health Agencies	140

In-Home vs. Institutional Cost

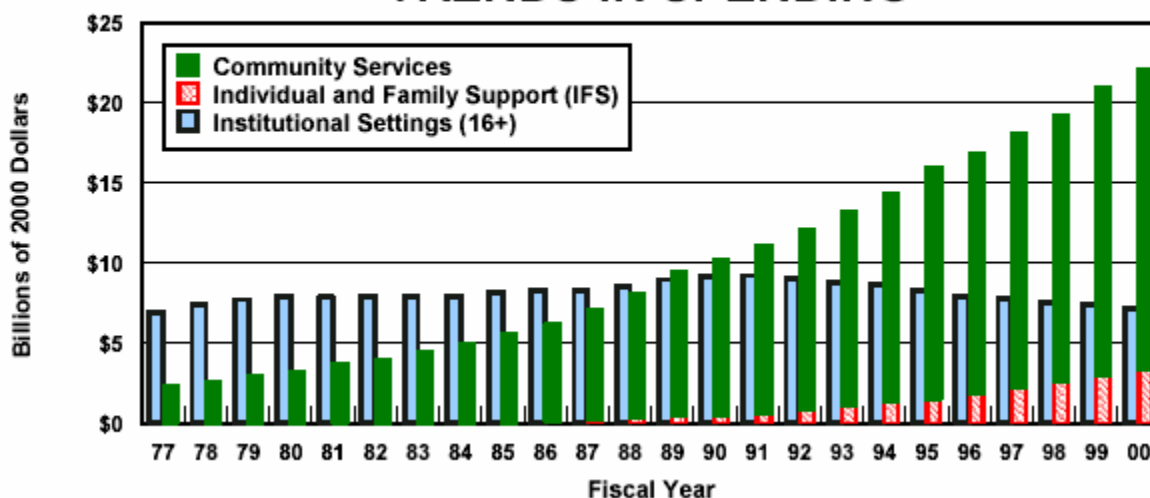
Average CHOICE and Aged and Disabled Medicaid Waiver Costs
Compared to Medicaid Nursing Facility Case Mix Average Rate*

	Average CHOICE Cost	Average A&D Waiver Cost	Nursing Facility Case Mix Average Rate
DAILY	Total		
State Share	\$19.82	\$10.58	\$38.20
Federal Share	-0-	\$17.30	\$ 62.42
TOTAL	\$19.82	\$27.88	\$100.62
MONTHLY			
State Share	\$602.86	\$321.93	\$1,161.92
Federal Share	-0-	\$526.15	\$1,898.61
TOTAL	\$602.86	\$848.08	\$3,060.53
ANNUALLY			
State Share	\$7,234.30	\$3,863.17	\$13,941.30
Federal Share	-0-	\$6,313.79	\$22,785.00
TOTAL	\$7,234.30	\$10,176.96	\$36,726.30

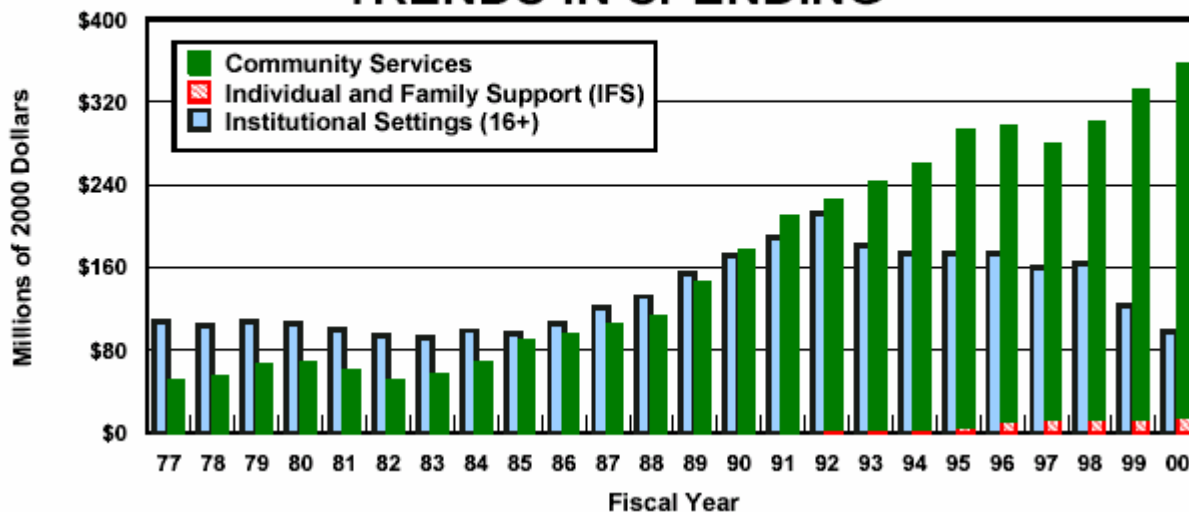
For example, the Muscatatuck State Development Center has 177 residents and an annual operating budget of \$56 million. This is approximately \$316,000 per person per year.

a. Community Services – Comparisons of Programs, Spending and Funding Sources for Developmental Disability Programs

UNITED STATES TRENDS IN SPENDING

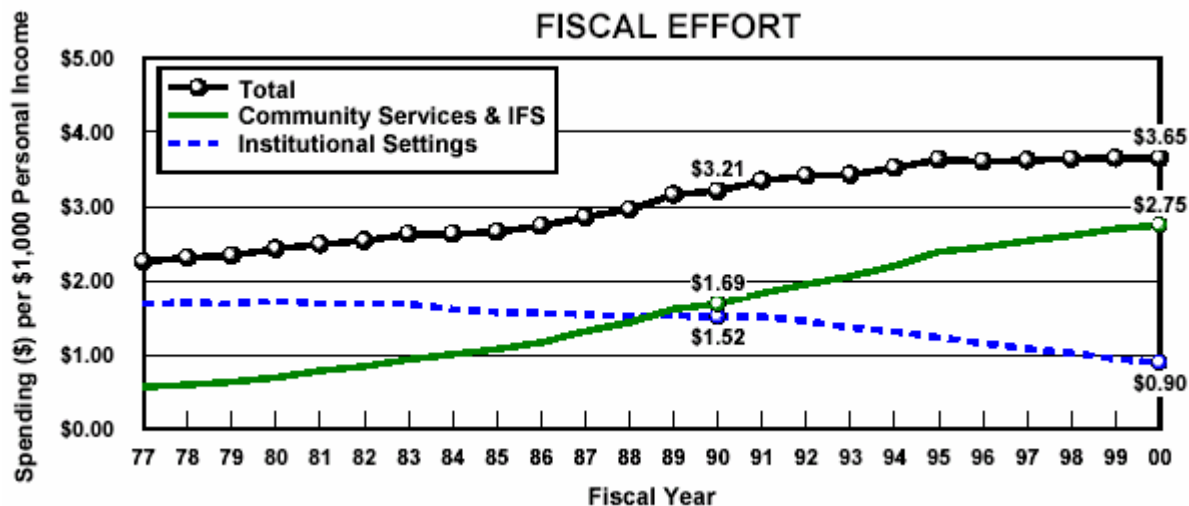


INDIANA TRENDS IN SPENDING

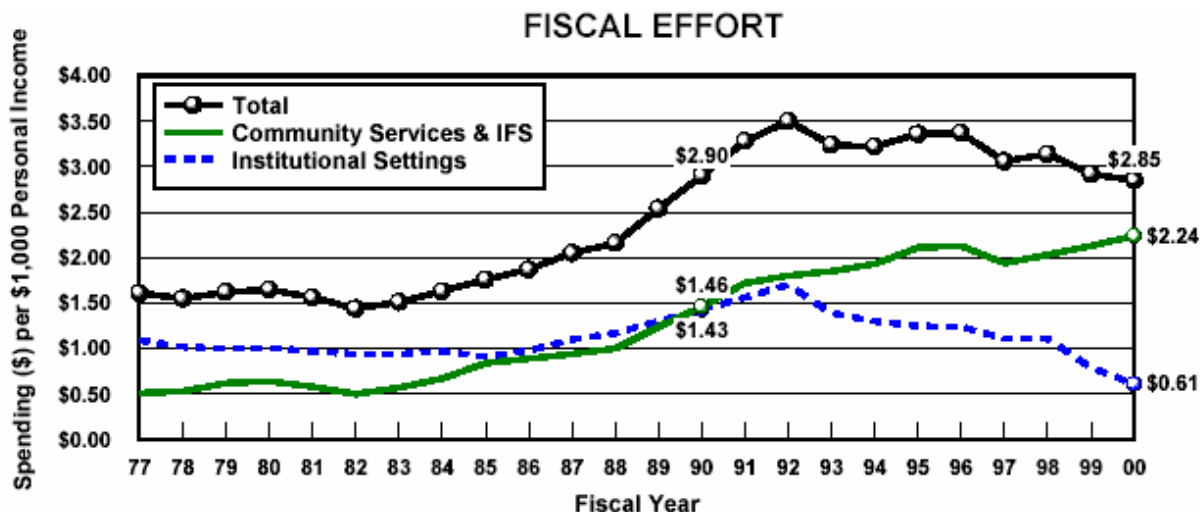


Indiana's shift in funding from institutional settings to community base services has been more dramatic than the national average. As reflected above, Indiana has increased its spending for home and community-based services by 620% since 1982. Over the same period, the U.S. as a whole has increased spending for home and community-based services by about 390%. Beginning in 1992, Indiana's funding for institutional settings began to decrease. From 1992 to 2000, the state reduced funding for institutional settings by 52%. For all states, the reduction over this period was only 16%.

UNITED STATES

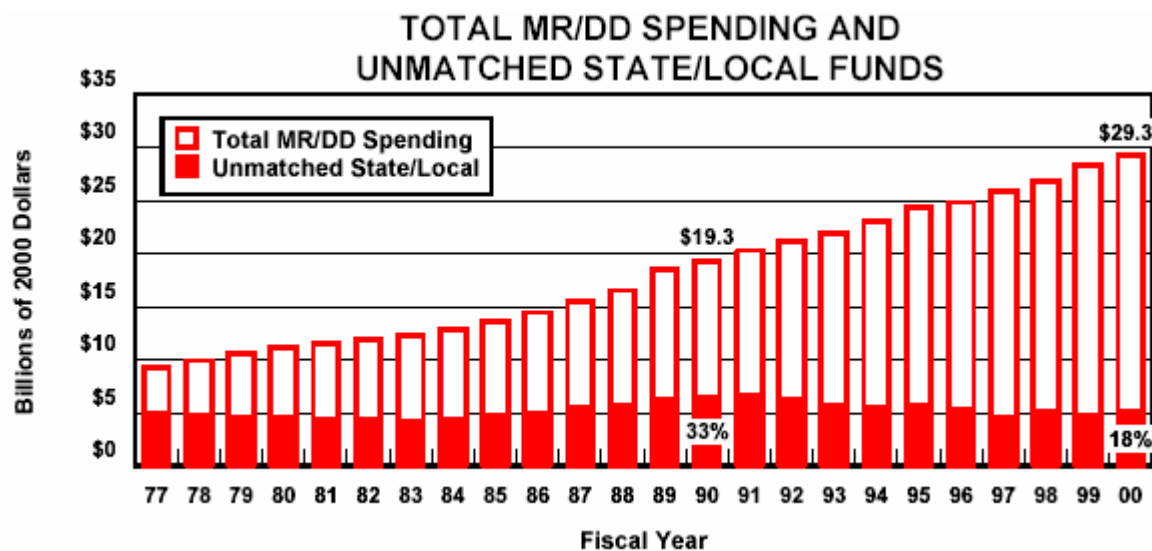


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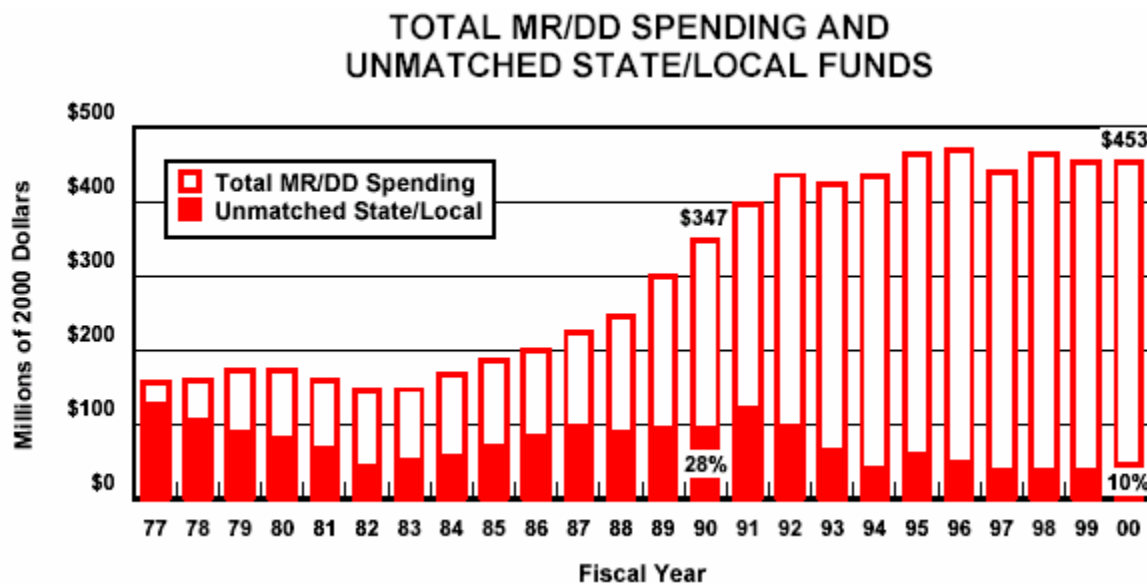


The Coleman Institute for Cognitive Disabilities measures **fiscal effort** as the amount spent services as a percentage of personal income. For community based services, Indiana's increase in fiscal effort since 1980 has been slower than the national average. Indiana has increased from \$0.70 per \$1,000 of personal income in 1980 to \$2.24 in 2000 – an increase of 220%. Over the same period, however the national average grew from \$0.75 to \$2.75, an increase of 266%. In 2000 dollars, Indiana's fiscal effort for community based services (\$2.24 per \$1,000 of personal income) represents about 81% of the national average of \$2.75.

UNITED STATES

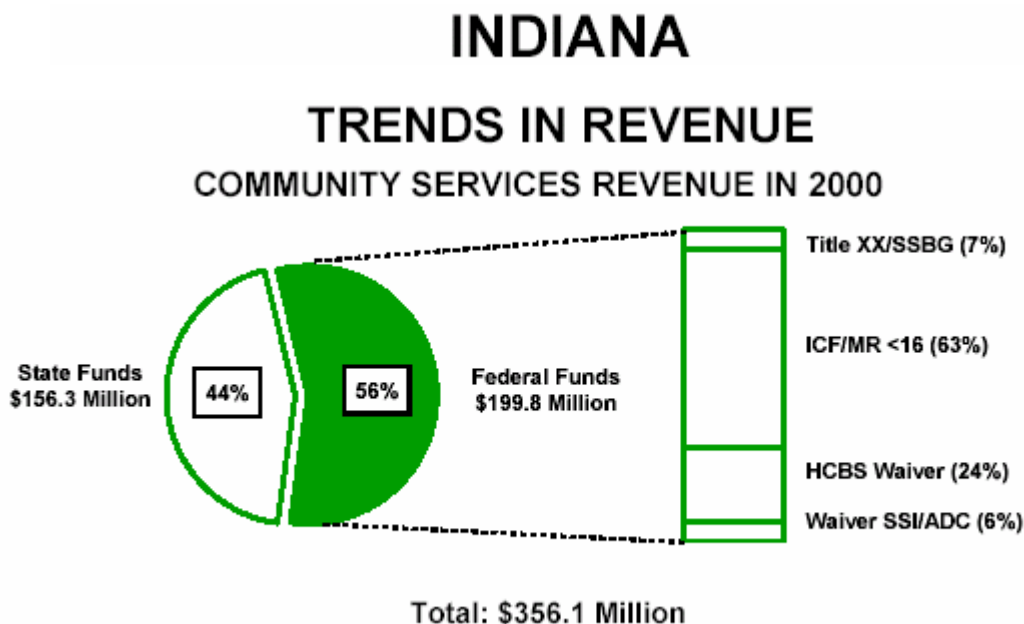
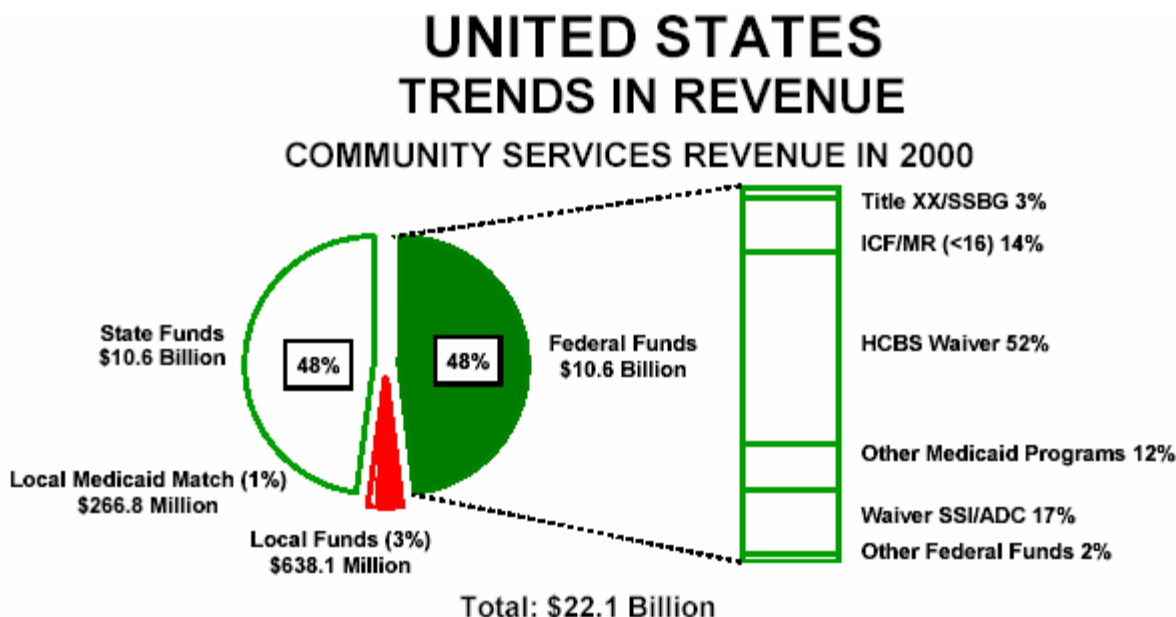


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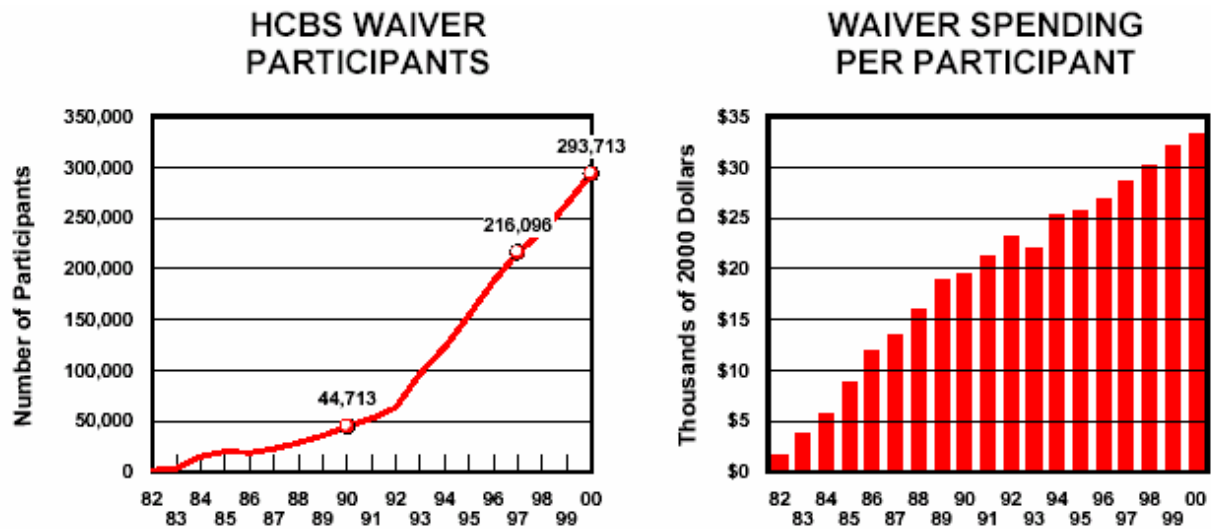


As shown in the chart above, Indiana began increasing spending for developmental disability (DD) services around 1982. In 2000 dollars, total state spending increased by 202% between 1982 and 2000. Over the same time period, the nation increased total spending for DD Services by about 144%.

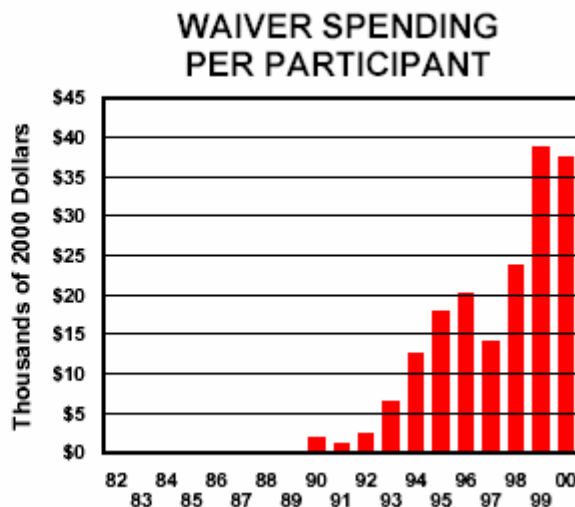
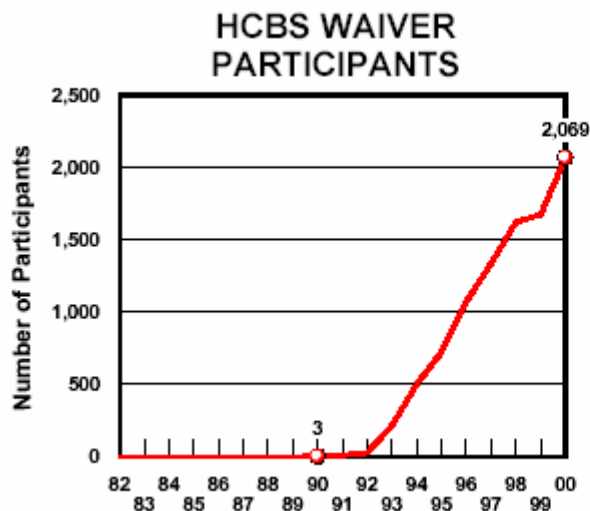
Another measure is the extent to which state and local funds are used to match, or leverage, federal funds. As of 2000, Indiana's level of unmatched spending was 10%. This compares to the national average of 18% for 2000. This leveraging effort is evident in the following charts as well.



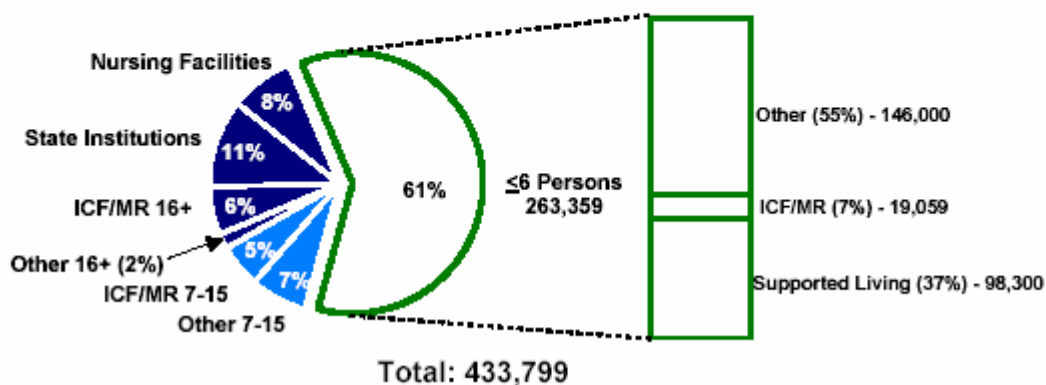
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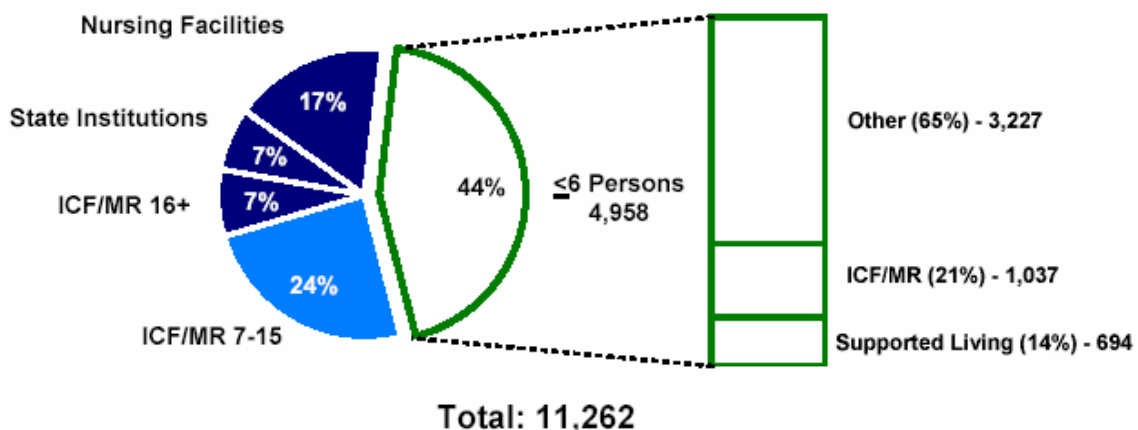
UNITED STATES TRENDS IN RESIDENTIAL SERVICES PERSONS SERVED BY SETTING IN 2000



INDIANA

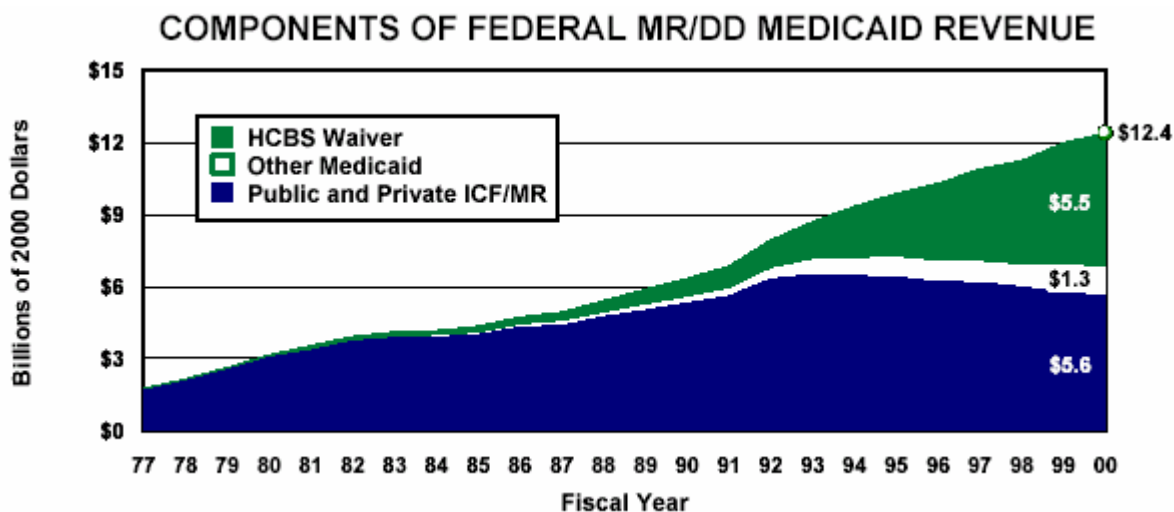
TRENDS IN RESIDENTIAL SERVICES

PERSONS SERVED BY SETTING IN 2000

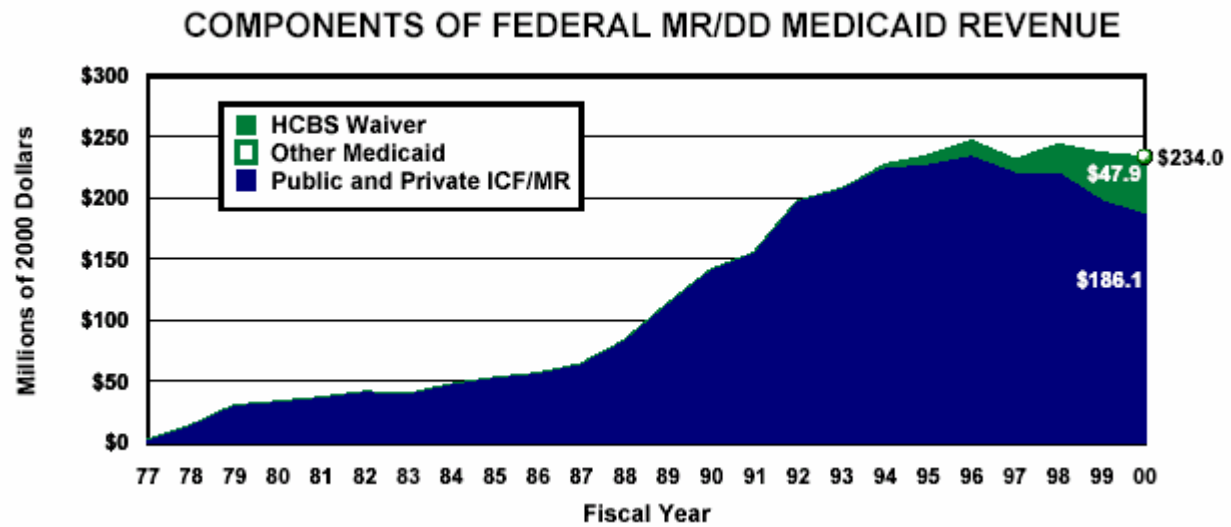


In terms serving individuals in smaller settings, Indiana lags behind other states. The national average in 2000 for individuals with developmental disabilities being served in settings of six people or less was 61%. In Indiana, however, the proportion was 44%.

UNITED STATES



INDIANA



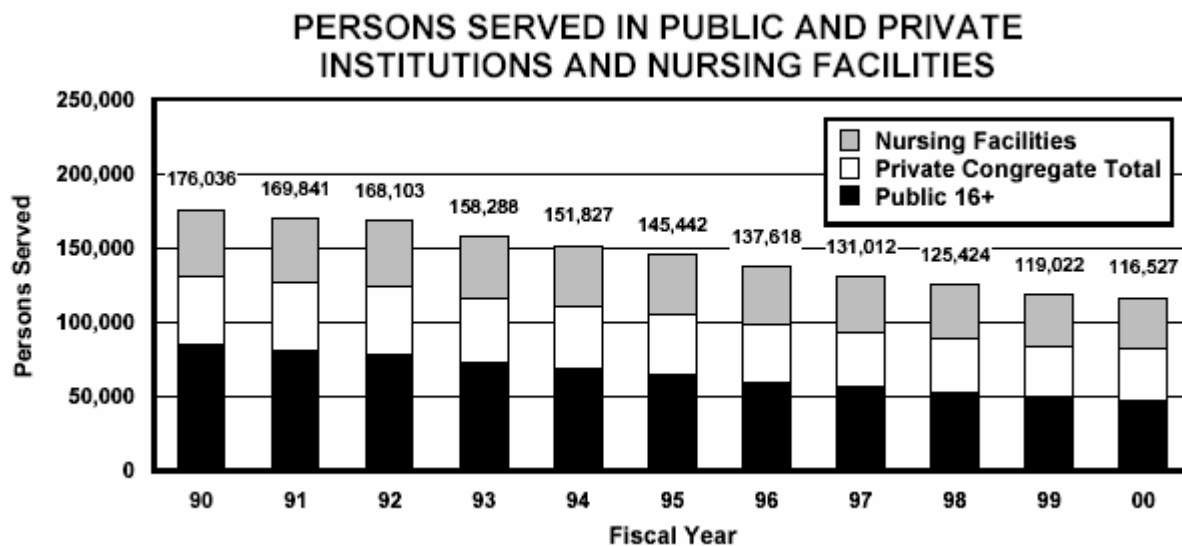
Trends in Persons Served By Setting -- Developmental Disabilities

Unites States									
	1990	----	1995	1996	1997	1998	1999	2000	10-Year Change
TOTAL	323,479		380,721	390,585	401,559	412,785	422,351	433,799	34.1%
16+ PERSONS	176,037		145,442	137,618	131,013	125,424	119,022	116,527	-33.8%
Nursing Facilities	44,903		40,249	38,960	37,229	36,252	35,132	34,743	-22.6%
State Institutions	84,818		64,187	59,775	56,343	52,754	49,276	47,374	-44.1%
Private ICF/MR	32,926		30,752	28,777	27,744	27,271	26,218	26,107	-20.7%
Other Residential	13,389		10,255	10,106	9,696	9,147	8,396	8,303	-38.0%
7-15 PERSONS	78,819		55,755	54,493	54,399	53,672	53,255	53,913	-31.6%
Public ICF/MR	4,027		4,434	1,579	1,594	1,431	1,259	1,368	-66.0%
Private ICF/MR	21,008		23,197	23,443	22,949	22,813	21,818	21,927	4.4%
Other Residential	53,784		28,124	29,471	29,856	29,428	30,178	30,618	-43.1%
≤6 PERSONS	68,623		179,524	198,475	216,148	233,689	250,074	263,359	283.8%
Public ICF/MR	300		775	983	1,275	1,192	1,079	1,137	279.0%
Private ICF/MR	8,940		17,303	18,001	19,083	19,269	17,904	17,922	100.5%
Other Residential	59,383		161,446	179,491	195,790	213,228	231,091	244,300	311.4%

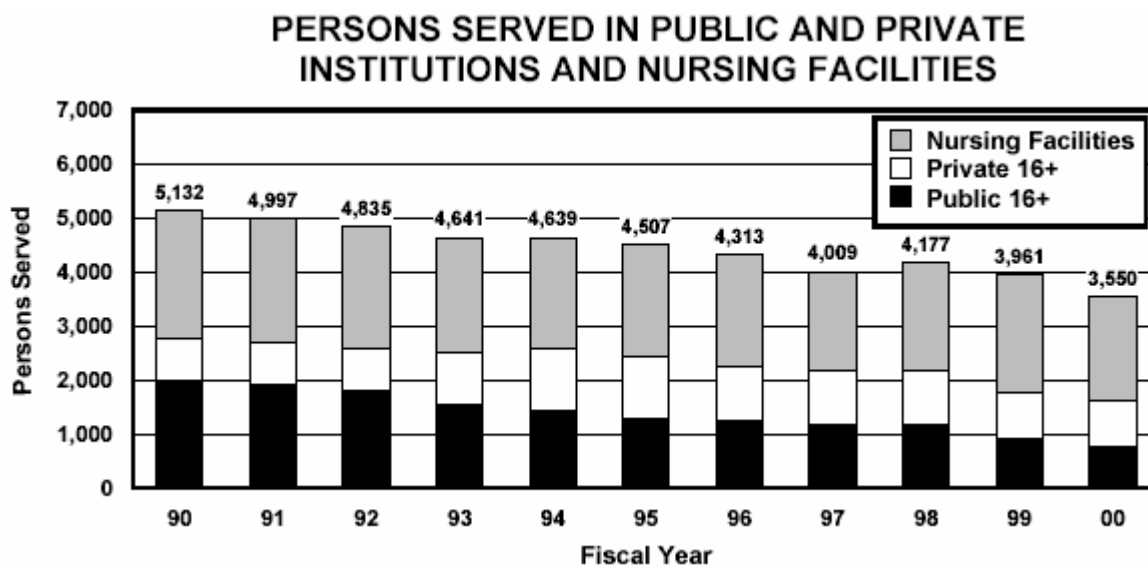
Indiana									
	1990	----	1995	1996	1997	1998	1999	2000	10-Year Change
TOTAL	9,659		10,152	10,297	10,643	11,199	11,671	11,262	16.6%
16+ PERSONS	5,132		4,507	4,313	4,009	4,177	3,961	3,550	-30.8%
Nursing Facilities	2,370		2,057	2,057	1,823	2,000	2,200	1,933	-18.4%
State Institutions	1,983		1,299	1,261	1,191	1,182	926	782	-60.6%
Private ICF/MR	779		1,151	995	995	995	835	835	7.2%
Other Residential	0		0	0	0	0	0	0	n/a
7-15 PERSONS	1,327		2,767	2,767	2,763	2,763	2,754	2,754	107.5%
Public ICF/MR	0		0	0	0	0	0	0	n/a
Private ICF/MR	1,327		2,767	2,767	2,763	2,763	2,754	2,754	107.5%
Other Residential	0		0	0	0	0	0	0	n/a
<6 PERSONS	3,200		2,878	3,217	3,871	4,259	4,956	4,958	54.9%
Public ICF/MR	0		0	0	0	0	0	0	n/a
Private ICF/MR	2,000		1,028	1,028	1,032	1,032	1,037	1,037	-48.2%
Other Residential	1,200		1,850	2,189	2,839	3,227	3,919	3,921	226.8%

Source: State of the States in Developmental Disabilities, 2001,
Coleman Institute for Cognitive Disabilities and Department of Psychiatry, University of Colorado

UNITED STATES



INDIANA



Governor's Commission on Home and Community Based Services
Data Book

State	Fiscal Effort	Ranking
Rhode Island	\$ 6.95	1
Maine	\$ 6.53	2
New York	\$ 5.99	3
North Dakota	\$ 5.72	4
Vermont	\$ 5.03	5
Minnesota	\$ 5.03	6
D.C.	\$ 4.61	7
Connecticut	\$ 4.47	8
Wyoming	\$ 4.25	9
West Virginia	\$ 4.01	10
New Mexico	\$ 3.98	11
Massachusetts	\$ 3.81	12
Idaho	\$ 3.81	13
South Dakota	\$ 3.76	14
Kansas	\$ 3.57	15
Oregon	\$ 3.44	16
Alaska	\$ 3.42	17
Ohio	\$ 3.35	18
Oklahoma	\$ 3.33	19
Montana	\$ 3.32	20
New Hampshire	\$ 3.30	21
Michigan	\$ 3.29	22
Pennsylvania	\$ 3.25	23
Wisconsin	\$ 3.22	24
South Carolina	\$ 3.16	25
Iowa	\$ 3.07	26
North Carolina	\$ 2.94	27
Louisiana	\$ 2.82	28
Arizona	\$ 2.76	29
Nebraska	\$ 2.67	30
Missouri	\$ 2.39	31
Arkansas	\$ 2.31	32
California	\$ 2.27	33
Indiana	\$ 2.24	34
Utah	\$ 2.23	35
Colorado	\$ 2.22	36
Washington	\$ 2.22	37
Maryland	\$ 2.11	38
Tennessee	\$ 1.99	39
Delaware	\$ 1.99	40
New Jersey	\$ 1.86	41
Illinois	\$ 1.74	42
Texas	\$ 1.73	43
Hawaii	\$ 1.34	44
Virginia	\$ 1.31	45
Alabama	\$ 1.28	46
Mississippi	\$ 1.24	47
Florida	\$ 1.13	48
Kentucky	\$ 1.07	49
Georgia	\$ 1.06	50
Nevada	\$ 0.72	51

Community Fiscal Effort and State Ranking, 2000

Note: Fiscal effort represents the proportion of total statewide personal income which is devoted to the financing of developmental disabilities community and Individual & Family Support services. Fiscal effort (Column 2) is expressed in \$\$ per \$1,000 of

Source: Braddock, Hemp, Rizzolo, Parish & Pomeranz. (2002). The State of the States in Developmental Disabilities: 2002 Study Summary. Boulder, CO: The Coleman Institute for Cognitive Disabilities and Department of Psychiatry.
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**HCBS Waiver Federal/State Spending as a % of Total Mental
Retardation/Developmental Disability Spending, 2000**

Rank (by waiver spending as % of total MR/DD spending)	State	Fed/State Waiver Funding	Number of Participants	Waiver Cost Per Participant	Waiver % of Total MR/DD Spending
1	Vermont	\$ 63,714,498	1,719	\$37,065	80%
2	New Hampshire	\$ 99,742,724	2,638	\$37,810	76%
3	New Mexico	\$ 110,293,519	2,160	\$51,062	70%
4	Rhode Island	\$ 145,595,178	2,471	\$58,922	68%
5	Colorado	\$ 203,772,399	5,799	\$35,139	64%
6	Arizona	\$ 227,104,692	10,816	\$20,998	62%
7	Wyoming	\$ 44,191,916	1,226	\$36,046	60%
8	Maine	\$ 127,940,702	1,840	\$69,533	59%
9	South Dakota	\$ 50,126,302	1,988	\$25,214	57%
10	Kansas	\$ 169,359,274	5,500	\$30,793	54%
11	Oregon	\$ 188,974,566	5,858	\$32,259	53%
12	West Virginia	\$ 85,143,110	1,910	\$44,578	53%
13	Minnesota	\$ 434,629,020	7,689	\$56,526	53%
14	Hawaii	\$ 22,952,448	1,089	\$21,077	50%
15	Alaska	\$ 31,112,865	681	\$45,687	50%
16	Nebraska	\$ 84,264,420	2,320	\$36,321	49%
17	Alabama	\$ 96,099,599	4,337	\$22,158	48%
18	Michigan	\$ 468,386,750	8,300	\$56,432	47%
19	Maryland	\$ 190,040,934	4,982	\$38,146	44%
20	Utah	\$ 73,724,680	3,147	\$23,427	44%
21	Connecticut	\$ 349,256,916	4,783	\$73,020	44%
22	Massachusetts	\$ 465,896,852	11,360	\$41,012	43%
23	Oklahoma	\$ 154,586,108	3,276	\$47,187	43%
24	Wisconsin	\$ 292,877,847	8,865	\$33,038	42%
25	Pennsylvania	\$ 660,766,466	15,943	\$41,446	42%
26	Montana	\$ 33,564,652	1,276	\$26,305	41%
27	Tennessee	\$ 188,112,207	4,318	\$43,565	40%
28	New York	\$ 1,697,262,148	38,696	\$43,861	40%
29	Delaware	\$ 31,502,716	489	\$64,423	36%
30	North Dakota	\$ 39,537,856	1,923	\$20,561	36%
31	Missouri	\$ 184,892,127	7,775	\$23,780	35%
32	Washington	\$ 189,515,894	10,530	\$17,998	35%
33	Florida	\$ 239,004,632	20,442	\$11,692	33%
34	Kentucky	\$ 60,418,737	1,200	\$50,349	32%
35	Virginia	\$ 144,459,211	4,698	\$30,749	31%
36	New Jersey	\$ 296,254,000	6,894	\$42,973	31%
37	South Carolina	\$ 113,050,202	4,489	\$25,184	28%
38	Georgia	\$ 100,768,711	3,612	\$27,898	26%
39	Nevada	\$ 13,150,358	950	\$13,842	22%
40	Iowa	\$ 83,874,760	4,591	\$18,269	21%
41	North Carolina	\$ 181,783,394	5,735	\$31,697	21%
42	Louisiana	\$ 95,425,105	3,450	\$27,659	19%
43	California	\$ 550,325,374	28,233	\$19,492	18%
*	44 Indiana	\$ 77,731,833	2,069	\$37,570	17%
	45 Texas	\$ 236,768,125	5,140	\$46,064	16%
	46 Arkansas	\$ 32,361,114	2,012	\$16,084	13%
	47 Illinois	\$ 148,731,384	7,400	\$20,099	13%
	48 Ohio	\$ 182,120,027	5,593	\$32,562	12%
	49 Idaho	\$ 14,883,847	653	\$22,793	11%
	50 Mississippi	\$ 4,421,843	848	\$5,214	2%
	United States	\$ 9,780,474,043	293,713	\$33,299	33%

6. Education

Education is an important component of achieving and maintaining independence. In Indiana, 82% of the population 25 or older has achieved at least a high school education. This can be compared to the national average of 80%.^{xxii}

According to the National Organization on Disabilities, 22% of Americans with disabilities fail to complete high school, compared to 9 percent of those without disabilities. It is also less likely for people with disabilities to have graduated from college than it is for people without disabilities (12% versus 23%).

The degree of disability has a significant impact on educational achievement. People with slight disabilities are more likely to complete high school (83%) and college (16%) than people with very severe disabilities (67% high school graduate; 9% college graduate), but they are still less likely to be high school and college graduates than people without disabilities (90% high school graduate; 23% college graduate).

Over the past fourteen years, the education gap has narrowed considerably between people with and without disabilities from 24 percentage points in 1986 to 13 percentage points today. In 1986, almost 4 out of 10 people with disabilities (39%) failed to complete high school, whereas today approximately 2 out of 10 people with disabilities (22%) have not completed high school.

The opposite is true for college attainment. There seems to have been a decline since 1998 from 30% to 26% among people with disabilities who have completed some college, and an even sharper decline from 19% to 12% for people with disabilities who have graduated from college. **XVII**

SECTION III: DOORS TO SERVICES

This section of the Data Book is designed to illustrate how individuals access services in Indiana. The intent is to highlight the process of accessing services if you are elderly, mentally ill, disabled, or if you are a child dependent on public services to access care.



1. **Division of Family and Children County Offices**

The Local Office of the Division of Family and Children is the place to apply for assistance for the following services:

- TANF
- Food Stamps
- Medicaid
- SSI eligibility determination
- Hoosier Healthwise (Medicaid programs for children)
- IMPACT
- Child Support Services
- Family Protection and Preservation

There is an Office of Family and Children in all 92 Indiana Counties that administer Public Assistance Programs and Family Protection and Preservation Programs. The local office is the appropriate place to apply for services. Once an application is filed with the local office, a caseworker is assigned and an appointment is set. The caseworker determines service need and financial eligibility based upon the information gathered in the application process. This process can be lengthy and require more than one visit to the local office. The process can be particularly burdensome to one with limited mobility or lack of transportation. Locations of Family and Children local offices can be accessed at

<http://www.in.gov/fssa/children/dfc/directory/index.html> or by phone at 317-232-4704.

2. **Area Agencies On Aging**

Applications for the following services are made at one of Indiana's Area Agencies on Aging:

- Developmental Disability Waiver;
- Support services Waiver;
- Title V: Senior Employment;
- Pre-Admission Screening;
- Congregate Meals;
- CHOICE

Indiana's Area Agencies on Aging provide case management and information and referral to various services for persons who are aging or developmentally disabled. They assist the elderly interested in employment or assistance with activities; parents of a child with a disability; a community member suspecting abuse and neglect of a dependent adult.

They also serve as the single point of entry for the IN-Home Services Program. There are 16 AAA agencies; the locations are listed at <http://www.state.in.us/fssa/elderly/aaa/index.html>, or by phone at 1-800-986-3505.

3. Community Mental Health Centers (CMHCs)

Applications for the following services are made at one of Indiana's Comprehensive Mental Health Centers:

- Medicaid Rehabilitation Option (MRO)
- Inpatient Services
- Residential Services
- Partial Hospitalization Services
- Outpatient Services
- Operate 72-hour Crisis Service
- Consultation-Education Services
- Community Support Program

Community Mental Health Centers (CMHCs) are the providers of mental health services on behalf of the Family and Social Services Administration Division of Mental Health and Addictions. There are thirty comprehensive mental health centers located throughout the state. Addresses can be accessed at <http://www.in.gov/fssa/servicemental/faq/2cchild&adoles.html> or by calling 1-800-901-1133

4. Vocational Rehabilitation Offices

Applications for these services can be made at one of Indiana's Vocational Rehabilitation Offices:

- Vocational Rehabilitation Services (VRS)
- Supported Employment (SE)
- Independent Living (IL) Services
- Assistive Technology through Awareness in Indiana (ATTAIN)

The Bureau of Vocational Rehabilitation provides quality, individualized services to enhance and support people with disabilities to prepare for, obtain or retain employment. Through active participation in their rehabilitation, people with disabilities achieve a greater level of independence in their work place and living environments.

Persons eligible for vocational rehabilitation services include: persons who have a physical or mental impairment; persons whose impairment constitutes or results in a substantial impediment to employment; persons who can benefit in terms of an employment outcome from the provision of vocational rehabilitation services; and persons who require services to help prepare for gainful employment.

There are twenty-five area vocational rehabilitation offices divided into five regions. A complete list of offices is available at <http://www.in.gov/fssa/servicedisabl/vr/offices.html> or by calling 317-232-7000.

5. State-Wide Network of Rehabilitation Facilities Working in Conjunction with The Bureau of Developmental Disabilities

Application for the following services are made at one of the local sites detailed below:

- Developmental Disability Day Services
- Autism Waiver
- Family Subsidy Program
- Case Management Services
- Diagnosis and Evaluations for Determine Status of Developmental Disability
- Traumatic Brain Injury Waiver
- Aged and Disabled Waiver
- Developmentally Delayed Waiver
- First Steps

The Bureau of Developmental Disabilities develops and administers a variety of services for people who have developmental disabilities. Services available for persons with disabilities are community-based residential alternatives to placement in state institutions and health facilities. Programs support independent living in the least restrictive setting possible and are based on a person-centered planning process. Access is available through nine district agencies throughout the state. A complete list of offices is available at: <http://www.in.gov/fssa/servicedisabl/field/index.html> or by calling 1-800-545-7763.

SECTION IV: PROGRAMS

1. Housing

A. Indiana's Housing Choice Voucher Program (Section 8)

Section 8 provides very low-income households with rental assistance. There are currently 3,700 households receiving housing assistance through this program. Two-thirds of those households have elderly or disabled members. However, demand is very high for this program and there are over 7,000 households on the pre-application list waiting for assistance.^{xxiii} In federal fiscal year 2001, Indiana received \$17.4 million dollars in funding for the Section 8 program from the US Department of Housing and Urban Development (HUD).

B. Section 8 Family Self-Sufficiency Program (FSS)

Indiana's Housing Choice Voucher Program and Family Self-Sufficiency (FSS) Program, administered by DFC's Housing and Community Services Section provide rental voucher assistance in conjunction with public and private-sector services and resources that can help residents of assisted housing achieve economic independence. Use of housing as a stabilizing force permits the families to invest their energy into other efforts including employment, education, and job training that are necessary to achieve self-sufficiency.

To be eligible, families must be current voucher holders. Participants in the FSS Program are provided with an opportunity to save for the future through the FSS Escrow Account. Increases in the family's contribution for rent, due to increases in earned income, are credited to an interest bearing escrow account. After the family successfully completes the program, the escrow balance can be withdrawn by the family to be used in any manner. Most FSS Program participants have used the escrow monies to continue working, buy an automobile or make a down payment on a home.

To date there have been 35 graduates of the program. The average escrow check amounts have been between \$3,500 and \$4,500. In the last 12 months, the FSS Program has awarded a total of \$59,134.96 to participants who have successfully completed the program. Participating Community Action Agencies, under contract with the Division of Family and Children manage the program throughout the entire year.

C. The Family Unification Program (FUP)

The program provides housing assistance vouchers to families with children at-risk of an out-of-home placement due to lack of adequate housing. HUD provides Indiana with funding for the program. There are 200 housing units available statewide under this program. Currently, all units are full.

D. The Mainstream Program

A joint DDARS and DFC initiative, the project is designed to provide rental assistance vouchers to enable persons with disabilities (elderly and non-elderly) to rent affordable private housing. The Program targets very low-income, disabled families who are on the Housing Choice Voucher waiting list of applicants. DDARS refers clients to the program, provides caseworker assistance to the eligible individuals in finding suitable housing, and

provides on-going case management and support. Mainstream Program recipients may live in mobile homes, apartments, doubles, single homes, etc. However, the program does not provide assistance to live in congregate settings such as nursing homes and schools.^{xxiv}??

2. Transportation

In CY2001, INDOT awarded more than \$1.7million in capital grants to over 60 counties and 83 non-profit social service agencies for vehicles and related equipment repair to ensure services for the elderly and disabled. It is estimated that these grants result in over 500,000 one-way trips (statewide) each year^{xxv}.

Although Medicaid-funded transportation services are provided only to persons receiving Medicaid and are provided only for Medicaid approved medical services, Indiana spent \$32,171,000 on Medicaid transportation services in SFY 2002. Even though these expenditures are significant compared to other Indiana transportation programs, Medicaid transportation expenditures represent less than 1% of total Medicaid expenditures. ^{xxxi}

3. Vocational Services

A. Vocational Rehabilitation Services (VRS)

Vocational Rehabilitation Services (VRS) is a State-Federal partnership program first established in 1920. The purpose of VRS is to assist eligible individuals with disabilities in achieving employment and independence. A major focus of the VRS program is to enable individual customers to have primary input into their own rehabilitation programs.

Eligibility for VRS is based on federal requirements. A person is eligible if he or she has a physical or mental impairment which is a substantial impediment to employment *and* he or she needs vocational rehabilitation services in order to enter, prepare for, engage in, or retain employment.

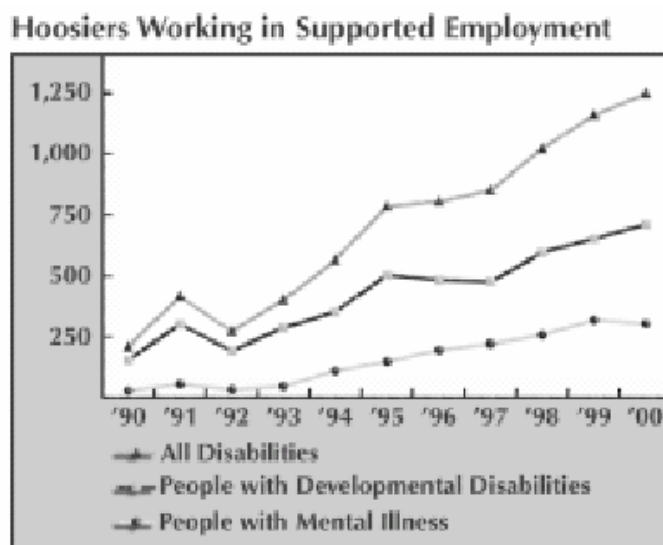
In FY 1999, 4351 Indiana residents were placed in employment through FSSA's Vocational Rehabilitation program, up from 3,641 in FY 1995.^{xxvi}

B. Supported Employment

Individuals with the most severe disabilities are placed in competitive jobs with qualified job coaches/trainers to provide individualized, ongoing support services needed for each individual to retain employment. The employer is contacted monthly and the employee is visited twice monthly to address any issues that may threaten the individual's ability to remain on the job.

DMHA provides the Office of Vocational Rehabilitation with funds to enable them to build supported employment programs. Now more than 26 community mental health centers offer supported employment programs throughout the state, a dramatic increase from the one CMHC offering such services in 1990. There are more than 700 people with Mental Illness in supported employment in Indiana at a cost of \$1.1 million.

Since 1999, an average of 772 individuals have been enrolled in supported employment programs each year.^{xxvii} Researchers at Ball State University have been collecting data from supported employment programs throughout Indiana, which shows that about 55 percent of those who enter a supported employment program will secure employment.^{xxviii}



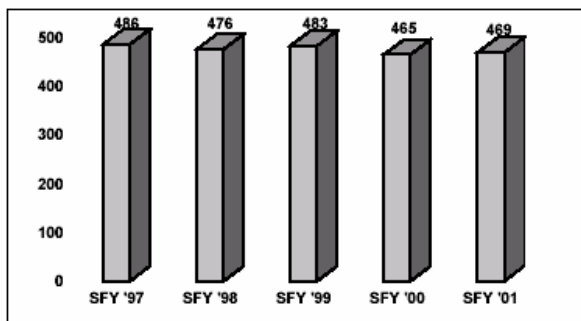
C. Senior Employment Program

The Older Americans Act of 1965 as amended authorized the establishment of the Title V Community Service Employment Program. This program is commonly referred to as the Title V Senior Employment Program. The purpose of the Title V Senior Employment Program is to provide meaningful part-time work opportunities in community service for low-income persons (below 125% of federal poverty) who are 55 years of age or older and who have poor employment prospects (as defined under 42 U.S.C. 1397). The desired outcome of this program is to provide meaningful employment and training to low-income persons who are 55 years of age or older and who have poor employment prospects. Initially, the U.S. Department of Labor subsidizes wages.

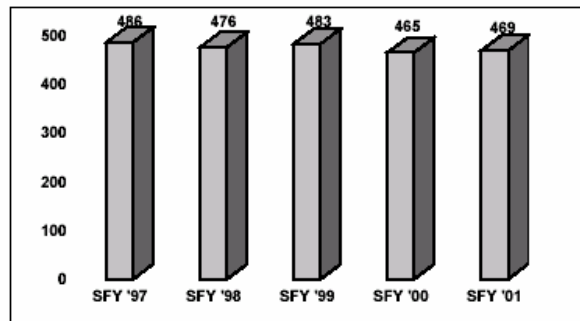
The Title V Senior Employment Program served 469 individuals during SFY 2001. The majority of individuals served were women between 60 and 74 years of age. The U.S. Department of Labor has established a goal of placing 20% of the Title V clients in unsubsidized employment. Indiana exceeded this goal by placing 21.2% of the clients in unsubsidized employment.

This program is funded primarily through the U.S. Department of Labor as authorized by the Older Americans Act of 1965 as amended. Federal funds equaling \$2,074,714 were expended in SFY 2001 and matched with \$340,625 in state and local funding. In addition, administrative expenses were \$68,979, of which 90% were federal dollars.

**Senior Community Services Program
Placements Below 125% of Poverty Level**



**Senior Community Services Program
Placements Below 125% of Poverty Level**



D. Impact

The Indiana Manpower and Comprehensive Training (IMPACT) Program provides services designed to help recipients of Food Stamps and TANF achieve economic self-sufficiency through education, training, job search and job placement activities

The IMPACT program assists participants to meet these goals through an approach that emphasizes job placement and job retention complemented by education and training activities. The participant's movement toward the goal is assisted by IMPACT case management, which coordinates an array of services, including education, training, job search, job placement, and social services offered by the Indiana Family and Social Services Administration through the Division of Family and Children and local providers.

IMPACT is Indiana's Welfare-to-Work program – a critical component of Indiana's welfare reform initiatives – which places an increasing emphasis on “work first.” “Work first” means that individuals are expected to accept a job which can be secured with their existing education and skills.

Waivers from the U.S. Department of Health and Human Services and the U.S. Department of Agriculture provide “work pays” incentives to assist recipients. Financial barriers to moving toward self-sufficiency have been reduced by Indiana's welfare reform initiatives. As an important link in the welfare reform program, IMPACT places an increasing priority on participants, retention, and wage gain with a “work first” focus along with a holistic approach to the whole family.

IMPACT is much more than a job training program, however, in that it seeks to address a broad range of barriers that clients may have in locating and maintaining employment.

From the time an individual applies for assistance, employment services are available and individuals are asked to begin their job search. For those not able to find a job right away, additional activities are provided. An assessment of the client's strengths and needs is completed and a case manager works with the client to develop an individualized plan for employment. The plan outlines the steps which will be taken for the client to become self-sufficient.

In addition to job search, the activities could include job readiness activities or an unpaid work experience at an agency. In addition to a work activity, appropriate vocational training or basic education classes might be included on the employment plan. The plan also includes supportive services such as transportation and child care.

To assist in this endeavor, the program has increased the provider contracts for job search, job readiness, job development, job placement and retention as well as providing services to the whole family and outreach to the faith-based community as service providers. Indiana was selected by the National Governors Association as one of seven states selected to pilot workforce innovations for the incumbent worker in partnership with the Indiana Department of Workforce Development and the Indiana Economic Development Council.

State Fiscal Year	Job Placements
1993	3,982
1994	4,665
1995	9,483
1996	19,906
1997	27,349
1998	33,500
1999	25,382
2000	23,216

E. Temporary Assistance to Needy Families (TANF)

TANF is a program that provides cash assistance and social services to assist the family, helping them achieve economic self-sufficiency.

Although the TANF Block Grant provides the funding for varied social services and benefits to low-income families, the primary program funded by the block is the cash assistance program.

Indiana's cash assistance program is part of the State's Welfare Reform Demonstration Project. This demonstration includes the employment and training services provided to those families receiving cash assistance. Those assigned to the demonstration treatment group are required to cooperate with policies which address personal responsibility, child immunization and school attendance, maintenance of a safe and secure home, prohibition of substance abuse and a 24-month time limit on cash assistance for those who are required to participate in employment activities. Additional provisions include more stringent penalties and employment incentives than the traditional AFDC Program. Those assigned to the control group are subject to the conditions of the former AFDC Program.

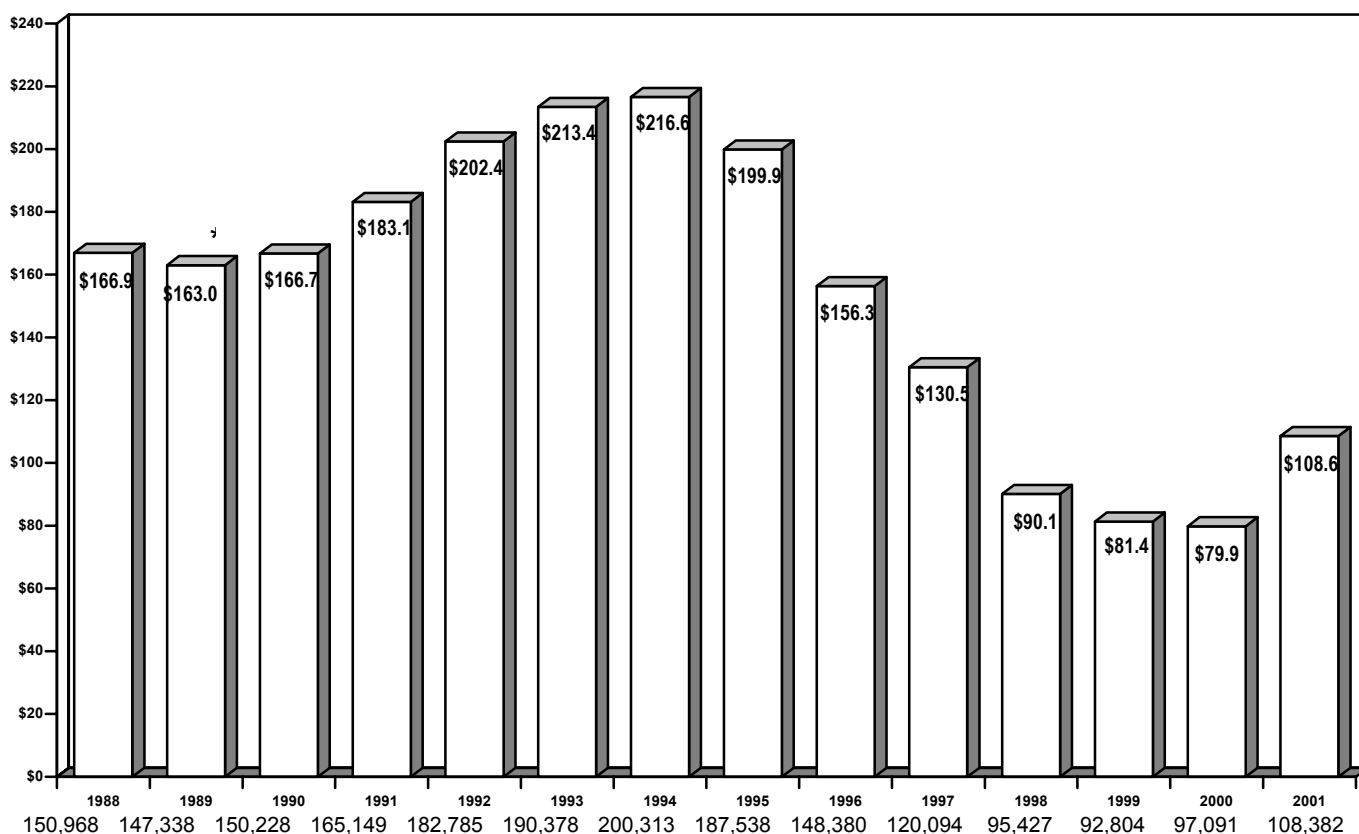
Families with children under the age of 18, that are deprived of financial support from a parent by reason of death, absence from the home, unemployment, or physical or mental incapacity. Assets are both liquid and non liquid so an applicant may not have assets valued in excess of \$1,000 at application. Subsequent to application, the Treatment Group has an asset limit of \$1500. In addition, individual members must provide their Social Security numbers and meet state residency and citizenship/alien requirements. Individual family members who do not meet exemption criteria must register for Indiana's Manpower Placement and Comprehensive

Training (IMPACT) program, as well as cooperate with the Child Support Enforcement Program.

Temporary Assistance For Needy Families Total TANF Regular Expenditures For State Fiscal Years 1988 - 2001

Millions Of Dollars

Monthly Average Recipients (excluding zero grants)



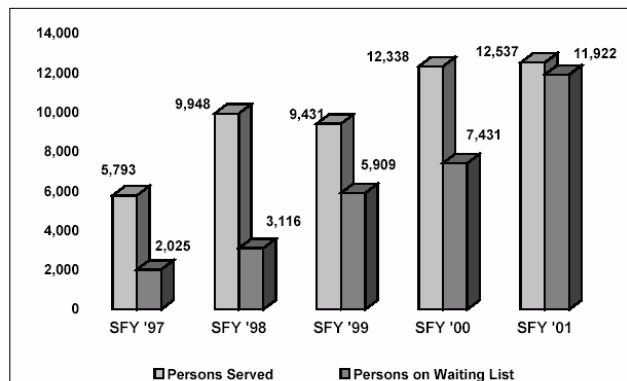
4. Community and Personal Assistance Support Services

A. The Community and Home Options to Institutional Care for the Elderly and Disabled (CHOICE) Program

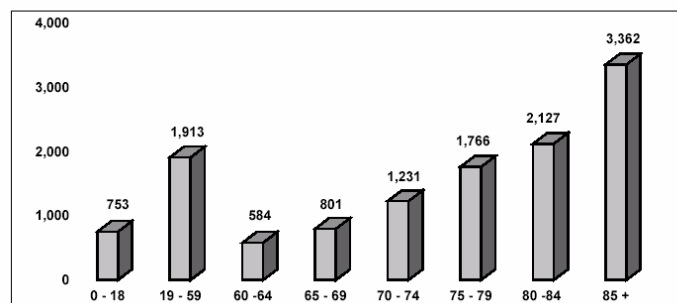
The CHOICE Program was established during the 1987 legislative session through House Enrolled Act (HEA) 1094 and began as a pilot program in Knox, Daviess, and Tippecanoe counties in 1988. The program went through several expansions that resulted in services to all of Indiana's 92 counties in 1992. The program is available to person age 60 years of age and older, or of any age with a disability and unable to perform two or more activities of daily living as determined by an assessment using the Long Term Care Services Eligibility Screen. In FY2001 the CHOICE program served 12,537 persons at a cost of \$38.8M. This translates

to roughly \$3,092.00/person. Despite serving more than 12,000 persons, more than 7,000 remain on the waiting list.

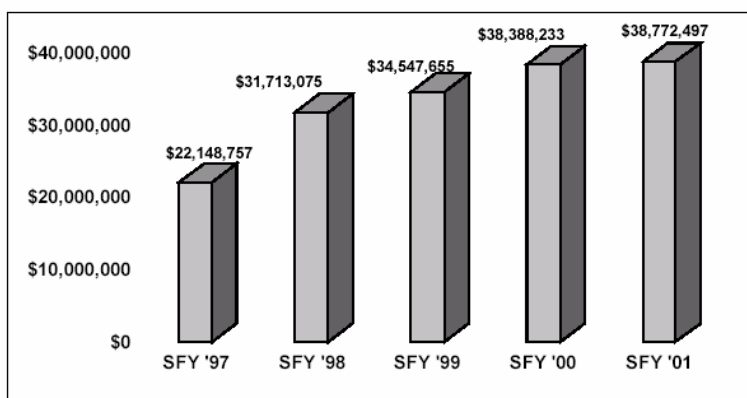
Persons Served by Community and Home Options to Institutional Care for the Elderly and Disabled (CHOICE) vs. Persons on Waiting List



Ages of Persons Served by CHOICE in SFY 01



CHOICE - Trend of Annual Expenditures



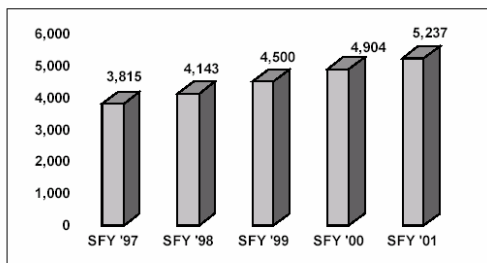
B. Waivers

Medicaid waivers allow Indiana to provide a variety of in-home and community-based services to individuals who would otherwise require the level of care provided in an institutional setting. These five Medicaid Waivers served a combined total of 5,237 individuals in SFY 2001 at a cost of \$133.3 million.

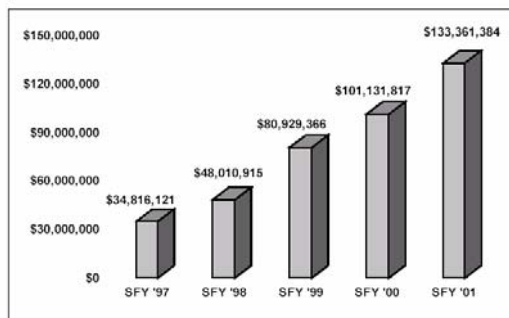
Governor's Commission on Home and Community Based Services

Dal Combined Home and Community-Based Waivers

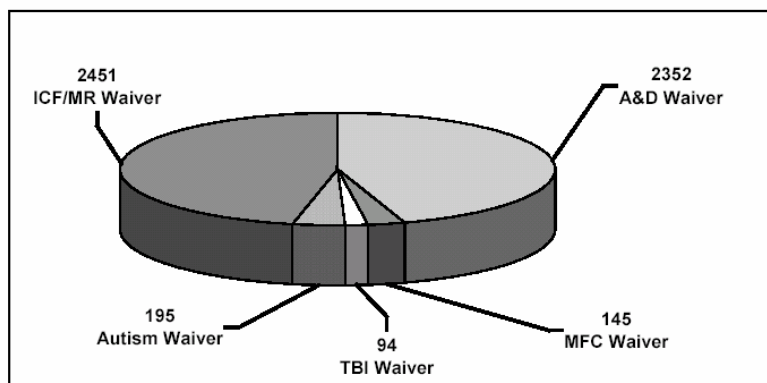
Persons Served Per Year



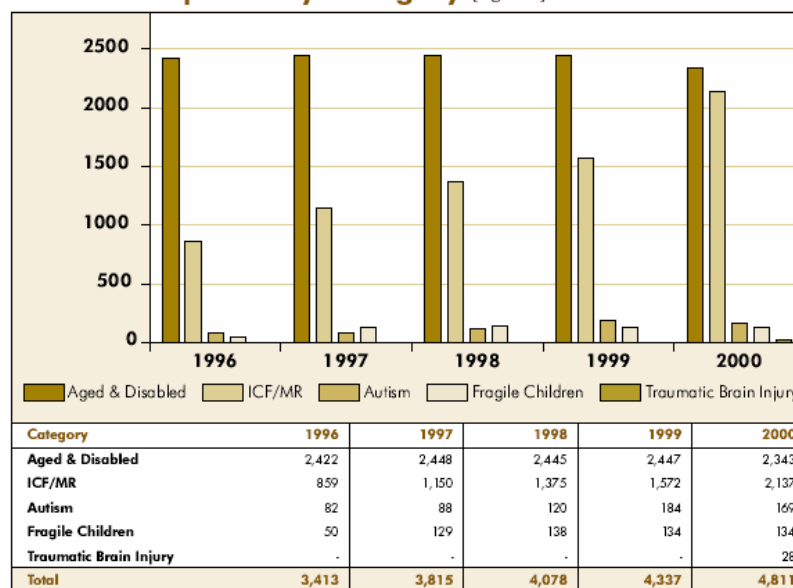
Combined Home and Community-Based Waivers Trend of Annual Expenditures



There are five Medicaid Waivers administered by DDARS, in 2001 allocated as such:



Waiver Recipients by Category [Figure 9]



Waiver waiting lists at end of year SFY 2002

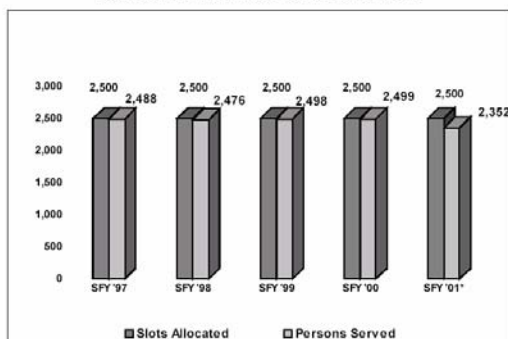
(www.in.gov/fssa/qtrreports.html)

Waiver Program	Waiting List as of 6/1/02
Aged and Disabled Waiver	2339
Autism Waiver	316
Developmental Disabilities Waiver	3473
Medically Fragile Children Waiver	222
Traumatic Brain Injury Waiver	80

i. Aged and Disabled Waiver

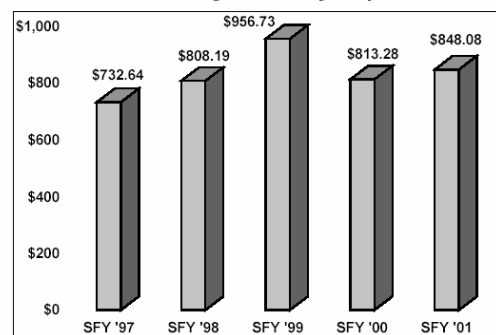
Serves individuals who meet the Medicaid guidelines and either 65 years of age or have disabilities. Individuals served by this waiver must meet level of care standards of a skilled or intermediate nursing facility

Aged and Disabled Home and Community-Based Medicaid Waiver
Persons Served and Slots Allocated



*The reduction in the number of persons served for SFY '01 resulted from a modification in the management of slot distribution. However, the modification was found to be inconsistent with DDARS processing time guidelines, and DDARS therefore has reverted to the previous management structure.

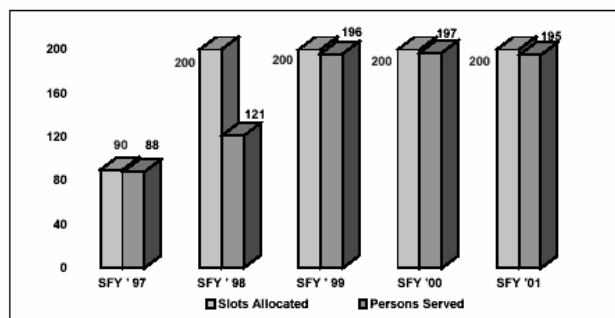
Aged and Disabled Home and Community-Based Medicaid Waiver
Per Person Average Monthly Expenditures



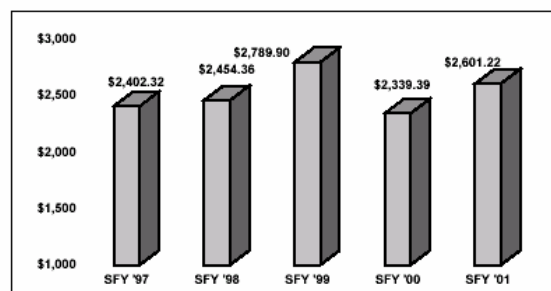
ii. Autism Waiver

Serves individuals with a diagnosis of autism who meet an intermediate care facility for mental retardation level of care

Autism Home and Community-Based Medicaid Waiver
Persons Served and Slots Allocated



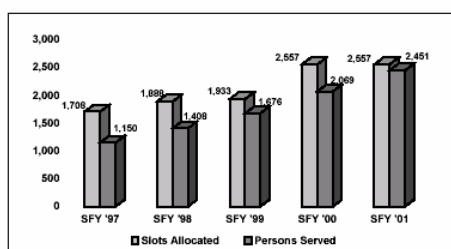
Autism Home and Community-Based Medicaid Waiver
Per Person Average Monthly Expenditure



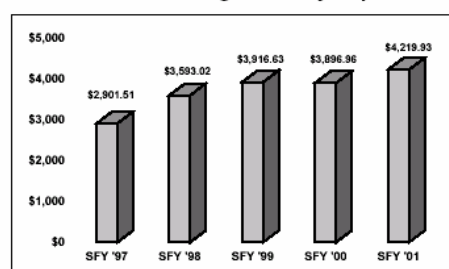
iii. Intermediate Care Facility for Mental Retardation (ICF/MR) Waiver

Serves individuals with developmental disabilities/mental retardation and other related conditions who meet intermediate facility for mental retardation level of care

ICF/MR Home and Community-Based Medicaid Waiver
Persons Served and Slots Allocated



ICF/MR Home and Community Based Medicaid Waiver
Per Person Average Monthly Expenditures



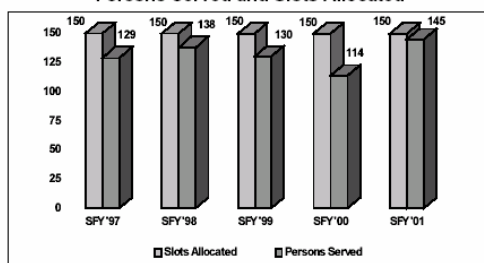
SFY 2000 Medicaid Payments
for ICF/MR [Table 9]

	Number of Unduplicated Residents	Total Payments	Annual Cost Per Resident
Group Home ICF/MR	4,176	\$199,873,533	\$47,862
Large Private ICF/MR	1,064	\$36,995,193	\$34,770
State ICF/MR	523	\$52,350,946	\$100,097

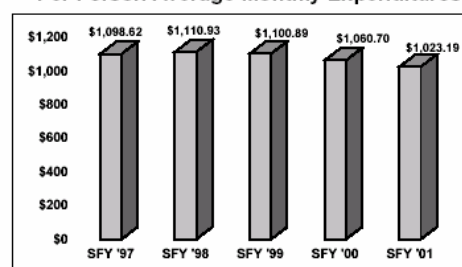
iv. Medically Fragile Children Waiver

Serves children under 18 years of age who are in need of significant medical services, including those who are technologically dependent. Recipients of these services meet either skilled nursing facility level of care or hospital level of care.

Medically Fragile Children Home and Community-Based Medicaid Waiver
Persons Served and Slots Allocated



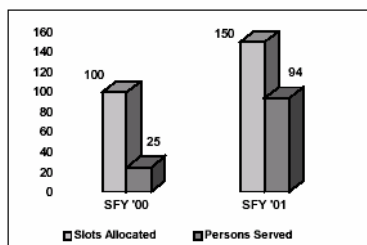
Medically Fragile Children Home and Community-Based Medicaid Waiver
Per Person Average Monthly Expenditures



v. Traumatic Brain Injury Waiver

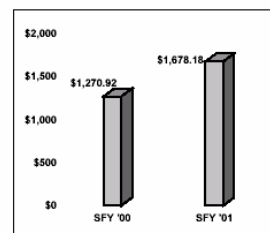
Serves persons who have suffered injuries to the brain including closed or open head injuries. Services under this waiver were implemented in March 2000.

**Traumatic Brain Injury Home and Community-Based Medicaid Waiver
Persons Served and Slots Allocated**



The Traumatic Brain Injury Home and Community-Based Waiver began services in March 2000, operating on a calendar year. Data for SFY '00 includes only a three month period.

**Traumatic Brain Injury Home and Community-Based Medicaid Waiver
Per Person Average Monthly Expenditures**



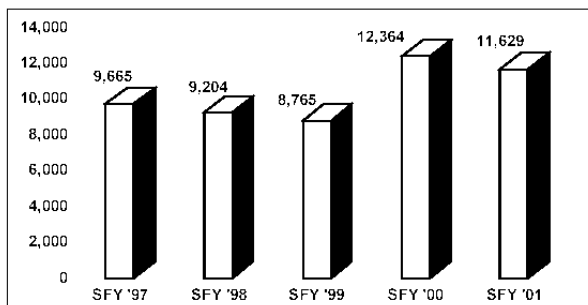
The Traumatic Brain Injury Home and Community-Based Waiver began services in March 2000, and therefore does not reflect a full year's expenditures. Data for SFY '01 includes a 12 month period and is an average of those 12 months.

C. Adult Protective Services

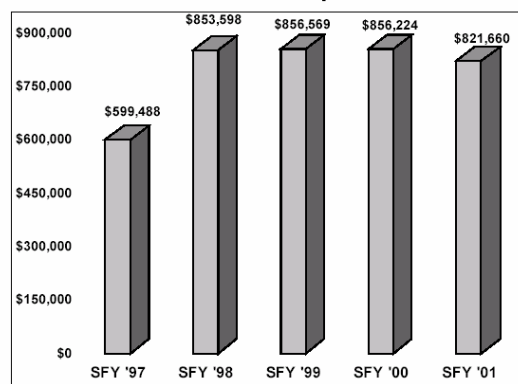
The purpose of the Adult Protective Services Program is to provide protection to adults who are endangered by abuse, neglect, or exploitation. The law defines "endangered adults" as individuals at least 18 years of age, incapable of caring for themselves, and being abused, neglected, or exploited.

Adult Protective Services served 11,629 Hoosiers in State Fiscal Year 2001. Program expenditures for that period were \$821,660.

**Adult Protective Services
Persons Served Per Year**



**Adult Protective Services
Trend of Annual Expenditures**

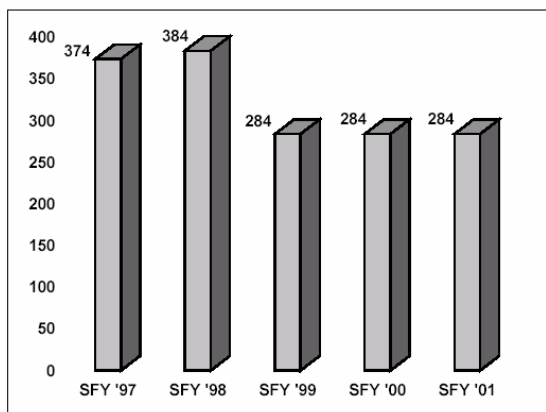


D. The Adult Guardianship (AGS) Program

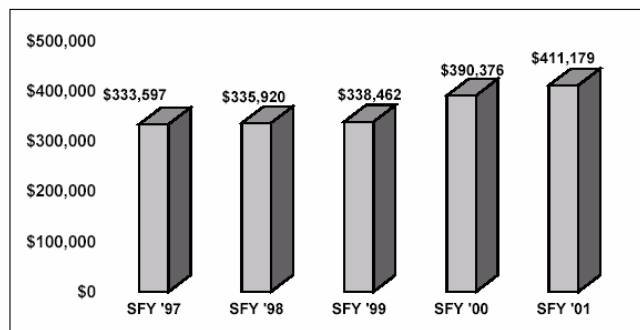
This program was established to provide full guardianships, limited guardianships, and less restrictive alternative services to indigent, incapacitated, adults who are unable to care for themselves and/or manage their own affairs without assistance, or who have a

developmental disability. The AGS Program served 284 individuals in SFY 2001. Total expenditures for that period were \$335,920.

**Adult Guardianship Services Program
Persons Served Per Year***



**Adult Guardianship Services Program
Trend of Annual Expenditures***



* Persons served per year reflects Adult Guardianship services that are funded with multiple resources, while trend of annual expenditures reflects only state funding. The reductions in persons served per year is primarily a function of changes in non-state funding, as state funding has increased in recent years.

E. Child Welfare Rehabilitation Option (CWRO)

The Child Welfare Rehabilitation Option is a new Medicaid waiver option that will provide clinical mental health services to individuals living in the community or in Residential Treatment Facilities who need aid intermittently or on a twenty-four hour a day basis for emotional disturbances or mental illness. Medicaid reimbursement will be available to current DFC licensed facilities and licensed child-placing agencies (LCPA). Indiana is requesting this option in order to leverage federal dollars. Currently, the costs of these services are being paid with 100% county funds. This waiver should be available sometime in CY 2003.

F. Child Support

The Bureau of Child Support helps Indiana's children and families by enforcing parental responsibility through collection of payments by non-custodial parents. The child support program provides a full range of child support including establishment of paternity, establishment and enforcement of child support orders, collection and distribution of child support payments, and location of absent parents.

Every child has the right to the care and support of both parents, whether or not the parents are married or both in the home. The child support program enforces this right. Child support services are offered through County Prosecutors Offices (one in each of the 92 Indiana counties).

These services include:

- Locating absent parents
- Establishing paternity
- Establishing and enforcing support orders
- Establishing and enforcing medical support orders

- Collecting current and past due support payments
- Review and adjustment of current support orders

G. Food Stamps

Indiana's Food Stamp Program is designed to raise the nutritional level of low-income households by supplementing their available food purchasing dollars with food stamp benefits. Information regarding nutrition and budgeting is available to participants to assist in choosing a nutritionally sound diet with limited income. Program participants are entitled to use their food stamp benefits at the retailer of their choice and choose foods based on their own preferences. However, retailers must be federally approved to accept food stamp benefits. Non-food items may not be legally purchased with food stamp benefits.

The Food Stamp Program is administered through each state but benefits are funded solely by federal funds. Federal regulations which govern implementation of the program are developed by the United States Department of Agriculture, Food and Nutrition Services section pursuant to federal legislation. In Indiana, the Family and Social Services Administration is responsible for ensuring that these federal regulations are initially implemented and consistently applied in each county.

The local Office of the Division of Family and Children in each of the ninety-two Indiana counties has the responsibility for processing applications, certifying eligible applicants for participation, and issuing benefits.

In order to qualify for food stamp benefits applicants/participants must meet both non-financial and financial requirements. Non-financial requirements include state residency, citizenship/alien status, work registration and cooperation with the IMPACT Program. The financial criteria are income and asset limits. If an applicant is eligible based on the federally established financial and non-financial requirements, the allotment of food stamp benefits they receive is based on their household size and net monthly income after all allowable deductions are subtracted.

The asset/resource limits are \$2,000 per household except for households containing a member age 60 or older; then the limit is \$3,000. Assets include bank accounts, cash, real estate, personal property, vehicles, etc. The household's home and surrounding lot, household good and personal belongings and life insurance policies are not counted as assets in the Food Stamp Program. All vehicles used for transportation are exempt beginning 3/1/02.

All households (except those with elderly or disabled members) must pass a gross income test (130 percent of poverty) to qualify for benefits. The gross income is per household size and based on the gross monthly income received by all household members.

Totals – Persons 331,206;
Total; dollars 297,964,712 (SFY 2001)

H. Family Protection and Preservation

FSSA's Bureau of Family Protection and Preservation (BFPP) and The Division of Family and Children local officers serve children in the state who are at risk of abuse or neglect. The BFPP administers programs that provide child welfare and family services, child abuse prevention services, foster care, adoption, independent living, residential licensing and youth

services. The BFPP provides child protection services to protect Indiana's children from further abuse or neglect and prevents, remedies, or assists in solving problems that may result in neglect, abuse, exploitation, or delinquency of children

The Family Preservation Program carries out the Division's goal to prevent unnecessary separation of children from their families by identifying family problems and assisting families in resolving them.

The program also seeks to return children who have been removed from their own homes to their families through the provision of services to the child and family problems and assisting families in resolving them.

The program also seeks to return children who have been removed from their own homes to their families through the provision of services to the child and family when a court finds that reunification is in a child's best interest.

The Family Preservation Program provides services to prevent out-of-home placement or to reunify children and their families in cases of substantiated reports of child abuse or neglect. Program services offered to families include education, counseling, visitation, sexual abuse treatment, parent aides, homemaker services, and home-based family services.

Approximately 12,5000 children and their family are separated at any given time. The state of Indiana has developed a five-year plan for family preservation and support services with the help of local Step Ahead councils and local service needs assessments. Federal Title IVB Part II monies fund the five-year plan.

Children in Need of Services (CHINS) By Type of Placement

	Total CHINS	Foster Homes	Residential Care	Adoptive Homes	Own Home	Relative Home	Other
March 2003	10,793	4,320	1,391	0	2,968	909	1,205
March 2002	9,981	4,109	1,315	12	2,594	850	1,101
% Incr (Decr)	8.1	5.1	5.7	(100)	14.4	6.9	3.4

CY 2002 Identified CHINS Costs

(Family & Children Fund)

Foster Homes Relative	4,239,002
Foster Homes Non Relative	24,820,858
Therapeutic Foster Homes	42,488,278
Residential Facilities	101,635,371
Independent Living	367,603
Preservation Services	15,901,499
Misc. Cost	<u>6,174,904</u>

Total CHINS

195,627,515

Family preservation expenditures largely reflect the cost of home and community-based services to children and their families who are under the supervision of the local office of family and children (court) and have been placed in their own homes. However, some of these costs are spent on home and community-based services to families of children who have not yet been returned home. The purpose of these services is to prepare the family for the return of the child.

As reflected in the table above, the cost of care for children in out-of-home placement is much greater than the cost of providing care to children at home. In March of 2002, for example, nearly twice as many Children in Need of Services were being served in their own homes compared to being served in residential facilities. The annual cost for residential facilities care in 2002 was more than six times greater than that of preservation services.

Family preservation expenditures largely reflect the cost of home and community-based services to children and their families who are under the supervision of the local office of family and children (court) and have been placed in their own homes. However, some of these costs are spent on home and community-based services to families of children who have not yet been returned home. The purpose of these services is to prepare the family for the return of the child.

Child Welfare Expenditures, 2000 (Actual) to 2003 (Budgeted)

	2000	2001	2002	2003
Community Based				Division
Family & Children Fund - Cal. Year	Actual	Actual	Final	Approved
Foster Homes	34,617,916	32,222,819	37,579,584	35,575,384
Therapeutic Foster Homes	40,090,952	42,304,579	46,998,682	48,279,729
Independent Living	388,420	438,367	919,010	1,085,027
Preservation Services	34,886,060	38,283,145	42,480,974	42,879,185
MRO	783,373	1,060,782	2,088,999	2,248,177
Adoption Services	36,531,177	45,597,986	51,257,395	59,407,342
Child Welfare Services (CWS)	6,322,682	6,597,595	9,266,490	8,923,470
Destitute Children	20,063	11,696	Included in CWS	Included in CWS
Contracted with the State - FFY	Actual	Actual	Actual	Budgeted
IV-E, Independent Living	928,348	573,364	1,438,383	2,088,263 *
IV-B, Part I (Services Only)	\$6,479,168	5,837,145	5,439,221	8,977,352 *
IV-B, Part II	3,449,171	3,410,345	2,674,202	7,819,282 *
Institutional Placements				Division
Family & Children Fund - Cal. Year	Actual	Actual	Final	Approved
Wards in Institutions	160,076,123	154,590,406	163,255,134	186,082,668
Prevention	Actual	Actual	Actual	Budget
Healthy Families	27,563,895	35,841,092	41,132,458	40,855,489
First Steps	31,428,952	54,078,028	58,930,670	63,729,758

I. First Steps Program

The First Steps Early Intervention System is Indiana's response to Part C of the Individuals with Disabilities Education Act. First Steps' broad definition of children with special needs, the exclusion of family income as consideration for eligibility, emphasis on family-focused intervention and efforts to provide services in the child's natural environment all combine to create a successful program whose population consists of those most in need of early intervention.

First Steps is based in each of Indiana's 92 counties and is implemented by a Local Planning Coordination Council in each of them. In SFY 2001, 16,272 infants and toddlers received services through the First Steps System. The estimated number of First Steps population is 18,000 children.

The program is available to children from birth to three years old who:

- Are experiencing developmental delay;
- Have a diagnosed condition that has a high probability of resulting in a developmental delay; and/or
- Are at risk of having substantial developmental delay as a result of biological risk factors if early intervention services are not provided.

Services available include the following:

- Speech therapy
- Occupational therapy
- Physical Therapy
- Developmental Therapy
- Social Work
- Psychological service
- Nutrition
- Health
- Nursing
- Medical Diagnostics
- Audiology
- Vision Services
- Assistive Technology
- Service Coordination
- Transportation
- Family Training
- Counseling

SFY 2002 First Steps expenditures from all funding sources:

First Steps Early Intervention Services (Part C Grant 2001)	\$7,830,010
Early Intervention (other sources)	\$52,809,390

J. Healthy Families

Healthy Families Indiana is a primary prevention program. It is a voluntary home visiting program for new parents as well as strategy for strengthening families and promoting healthy child outcomes. A variety of services are provided including child development, access to health care and parent education. By working closely with hospital maternity wards, prenatal clinics and other local agencies, the program systematically identifies, either before or immediately after birth, families who would benefit from education and support services and offer them home visitor services. In partnership with Healthy Families America, the national home visitation model, Healthy Families Indiana was launched in 1994. Prevent Child Abuse America and Healthy Families America credentialed Healthy Families Indiana as a multi-site system on September 25, 2001.

Indiana has the first Healthy Families program in the nation to support a state system with blended federal funds through the establishment of a Healthy Families Fund. Indiana is also the first state to establish formal linkages with the U.S. Justice Department.

At the state level, four revenue sources contribute to the overall funding: Children's Trust Fund, Indiana Criminal Justice Institute, FSSA Division of Mental Health and Addictions, and TANF funding through the FSSA Division of Family and Children.

The program is designed to strengthen families by reducing the incidence and possibility of child abuse and neglect, childhood health problems and juvenile delinquency.

The goals of Healthy Families Indiana are to systematically identify overburdened families; promote healthy family functioning by teaching problem solving skills; reduce family stress; improve family support systems; promote positive parent/child interaction; promote health childhood development; prevent child abuse and neglect; and promote self sufficiency by linking families to existing community resources.

Healthy Families Indiana provides screening and assessment of families in targeted areas throughout the state. Service entry points include WIC programs, health clinics and local hospitals. Parents are screened using a validated, standardized instrument, and the Maternal Record Screen. Positive screens do not assess the risk of child abuse and neglect but do indicate a need to conduct a more in-depth discussion with the family.

Families with positive screens are then assessed using a standard validated instrument, the Kempe Family Stress Checklist which is scored using a standardized rating scale. Families with a score of 25 or higher are offered the opportunity to participate in a voluntary home visiting program tailored to their individual needs.

The 56 Healthy Families Indiana program sites provide services to families throughout the state. The number of families served has increased from 760 in 1994 to 21,401 in 2001. Healthy Families has grown from a \$600,000 child abuse and neglect program in 1994 to \$40.5 million in 2001. Funding is a combination of local, state, and federal dollars.

Descriptive data provided by Healthy Families Indiana sites during 2000 - 2001 have revealed the following results:

- Of the 4,000 families screened each month, 45% had a positive screen and nearly 20% had a positive assessment;
- 90% of the children had a regular primary health care provider and over 70% kept regularly scheduled well child visits;
- 75% received age appropriate Denver II Developmental Screenings and 80% were up to date on childhood immunizations;
- 3% of the families experienced a subsequent pregnancy;
- 28% of mothers who have not graduated from high school are enrolled in school or a GED program; and
- Over 98% of the families served in the largest Indiana site who had at least 24 home visits had no substantiated abuse or neglect while in the program despite the fact they were at higher risk.

K. Other Pertinent Services

- In State Fiscal Year 2001, more than 1.4 million congregate and 1.4 million home delivered meals were provided in Indiana.^{xxix}
- Furthermore, \$9 million was spent on Room and Board Assistance and \$2.7 million was spent on Assistance to Residents of County Homes.

FY 2000 Profile of Indiana Older American Act Programs ^{xxx}		
Title III/VII Services	60+ Persons Served	Service Units
Personal Care	892	65,611
Homemaker	6,273	212,353
Chore	1,705	35,723
Home Delivered Meals	27,781	3,160,258
Adult Day Care/Health	457	150,196
Case Management	43,537	185,162
Congregate Meals	41,325	2,427,756
Nutrition Counseling	3,873	22,985
Assisted Transportation	7,673	187,633
Transportation		1,321,712
Legal Assistance		24,543
Nutrition Education		88,018
Information and Assistance		250,635
Outreach		527,357

SECTION V: GLOSSARY OF TERMS, ACRONYMS, AND RELEVANT AGENCIES

AAA

Area Agencies on Aging – (also known as Area Agencies or Triple A) Sixteen nonprofit agencies located throughout the state which provide services, and grant or contract with other public and private organizations to provide services, for older persons within their area. In Indiana, they are responsible for administering federal and state funding for community and in-home long term care services for the aged and disabled.

ACT

Assertive Community Treatment - a very intensive case management approach for high-risk individuals with severe mental illnesses. The model for ACT involves maintaining housing, living independently, home visits, and medication management assistance by trained staff.

ADA

Americans with Disabilities Act - Enacted July 26, 1990. The ADA prohibits discrimination and ensures equal opportunity for persons with disabilities in employment, State and local government services, public accommodations, commercial facilities, and transportation. It also mandates the establishment of TDD/telephone relay services.

ADLs

Activities of Daily Living – A measurement of a person's degree of independence in walking, getting in and out of bed, bathing, dressing, eating, toileting, and taking medicine. Also see "Custodial Care."

Adult Day Care or Adult Day Care Services

Care generally offered by a social service agency or nursing home, usually custodial care in nature. Similar concept as children's day care centers, but catering to adult needs and interests.

Adult Protective Services

Investigates and resolve reports of abuse, neglect, or exploitation, and to assist in obtaining protective services for endangered adults.

AOA

Administration on Aging – A federal agency under the U.S. Department of Health and Human Services. AOA provides home and community-based services to older persons through the programs funded under the Older Americans Act. Programs include home-delivered meal programs, nutrition services in congregate settings, transportation, adult day care, legal assistance, ombudsman services and health promotion programs.

Assisted Living Facility

Provides home and community services in a more home-like and comfortable environment than the typical nursing home setting. Services are designed around the resident's needs. Provides a combination of social interaction and privacy. Nursing staff provide nursing services in licensed assisted living facilities. These services are provided by a home care agency in unlicensed assisted living facilities.

Assistive Technology

Assistive technology device means any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities. Assistive technology service means any service that directly assists an individual with a disability in the selection, acquisition, or use of an assistive technology device.

Benefit Period

The period of time for which the insured is eligible to receive benefits or services under Medicare, Medicare Supplement, or a Long Term Care insurance policy

Benefit Period under Medicare

The Medicare Part A benefit period begins upon entry to a qualified hospital, and ends when the patient has been out of a hospital (and not receiving Medicare benefits in a facility that primarily provides skilled nursing or rehabilitation services) for 60 consecutive days, including the day of discharge. The Part B benefit period is based on the calendar year.

Medicare Part A can cover inpatient hospital care, skilled nursing facility care, home health care and hospice care. Medicare Part B includes a wide range of services including outpatient hospital services (e.g. radiology and laboratory tests, therapy services, medical supplies, and durable medical equipment), physician services and home health care. In a skilled nursing facility (following a qualified hospital stay), Medicare Part A will pay in full for Day 1- 20 and for Days 21- 100 a co-insurance amount of \$101.50 per day in 2002 is required. A beneficiary qualifies for a new 100-day benefit period when there are 60 days during which there has been no inpatient stay, no Medicare SNF stay, and no inpatient care for a continued skilled level of care. The Part B benefit period covers specific services based on the calendar year.

BI or TBI

Brain Injury or Traumatic Brain Injury– There are currently 5.3 million Americans living with a disability caused by brain injury. Brain injury is acquired damage to the brain, the result of either an external physical force or internal causes, which results in an impairment of cognitive, emotional, and/or physical functioning. It is not of a degenerative or congenital nature but caused by an external physical force or by internal damage such as anoxia (lack of oxygen), stroke, disease, or tumor. It may produce a diminished or altered state of consciousness, which results in impairment of "thinking processes" and physical abilities. These impairments may be either temporary or permanent, and cause partial or total functional disability or psychosocial maladjustment.

BAIHS

Bureau of Aging and In-Home Services- a part of Family and Social Services Administration/ DDARS. BAIHS administers four Medicaid waivers, CHOICE, and other home and community-based services for people who have disabilities or are aging.

BDDS

Bureau of Developmental Disabilities Services- a part of Family and Social Services Administration/ DDARS that administers developmental disabilities services programs, including three Medicaid waivers.

Case Manager

An individual qualified by training and/or experience to coordinate the overall medical, personal, and social service needs of the patient. Someone who coordinates/manages the patient's care or "case."

Case Management

The coordination and monitoring of treatment and services.

CHOICE

Community and Home Options to Institutional Care for the Elderly and Disabled – One of Indiana's in-home services programs administered by the sixteen Area Agencies on Aging.

CMHC

Community Mental Health Centers- state, local, or non-profit entities. They are contracted by the Indiana Division of Mental Health to provide a full range of mental health services within

a designated geographical area. They also provide a "gatekeeper" function to monitor each individual from the time the individual was committed to a state institution administered by the division until the individual is discharged from the commitment. They provide services regardless of a client's ability to pay.

CMS

Centers for Medicare and Medicaid Services – A branch of the Department of Health and Human Services. This federal agency is responsible for administering the Medicare and Medicaid programs and approves all waivers and waiver amendments. Formerly HCFA (Health Care Financing Administration).

Convalescent Care/Rehabilitative Care

Non-acute care prescribed by a physician and received during the period of recovery from an illness or injury.

Conversion

For the purpose of the Medicaid waiver, the closing of a Medicaid funded facility or a portion of the facility, and the conversion of the facility's bed capacity to Medicaid waivers. The facility must have a closure or downsizing plan approved by the state in order to allow the funding to follow the person into the community. Also refers to the "systems change" of community rehabilitation programs from the provision of segregated services, i.e. sheltered workshops, to integrated services, i.e. supporting people in competitive employment in the community

CPS

Child Protective Services –Protects Indian's children from further abuse or neglect and prevents, remedies, or assists in solving problems that may result in abuse, neglect, exploitation, or delinquency of children.

Custodial Care

Care is considered custodial when it is primarily for the purpose of meeting personal needs and could be provided by persons without professional skills or training. Example: help in walking, getting in and out of bed, bathing, dressing, eating, toileting, and taking medicine. (These may also be referred to as Activities of Daily Living or ADLs.)

CWRO

Child Welfare Rehabilitation Option – New Medicaid waiver option that will provide clinical mental health services to individuals living in the community or in Residential Treatment Facilities. Recipients will be those who need aid intermittently or on a twenty-four hour a day basis for emotional disturbances or mental illness. This option is being sought to leverage federal dollars to cover the cost of services that are currently being paid with 100% county funds. Waiver should be available sometime in CY 2003.

DAPW

Division of Public Works (<http://www.in.gov/idoa/pwd/>)- As a key branch of the Indiana Department of Administration (IDOA), the Public Works Division (DAPW) manages almost all of the building construction and maintenance projects for the State of Indiana. This includes evaluation of construction proposals for feasibility; designing the projects; advertising, public bids, and awarding construction; and managing these construction contracts through final completion. In past years, DAPW has administered more than 1000 design and construction projects annually, with an average estimated value in excess of \$70,000,000.

DDARS

Division of Disability, Aging and Rehabilitative Services – a part of Family and Social Services Administration. Includes Bureau of Aging and In-Home Services, Bureau of Developmental Disabilities Services, Bureau of Rehabilitative Services, Bureau of Fiscal Services and the Bureau of Quality Improvement Services.

DD

Developmentally Disabled - A developmental disability is distinguished from other disabling conditions in that it occurs during the developmental years of an individual's life, usually before the age of 18. Although the federal law does not define specific disabling conditions, persons with mental retardation or autism are generally developmentally disabled. Persons diagnosed as having a condition such as moderate or severe cerebral palsy may also be considered developmentally disabled. In addition, the 10- 15 percent of those persons with epilepsy who experience uncontrolled seizures also fit the definition of developmentally disabled.

DFC

Division of Family and Children – A state agency that strengthens families through services that focus on prevention, early intervention, self-sufficiency, family support and preservation. The division administers child welfare, Food Stamps, employment and training services for low-income clients, and Medicaid eligibility.

DHHS

Department of Health and Human Services – The federal agency that administers the Medicare Program through its divisions, the Social Security Administration and Centers for Medicare and Medicaid Services (CMS) – previously HCFA.

DME

Durable Medical Equipment – this is equipment which can: 1) withstand repeated use; 2) is primarily and customarily used to serve a medical purpose; 3) generally not useful to a person in the absence of an illness or injury; and 4) is appropriate for use in the home.

DMHA

Division of Mental Health and Addiction – division of the Indiana Family and Social Services Administration.

DOE

Department of Education

DOE/ DEL

The Division of Exceptional Learners, Indiana Department of Education- administers the Individuals with Disabilities Education Act (IDEA, P.L. 101-476), which applies to students with disabilities, ages 3 through 21, in Indiana. Included in this Act are students with autism, deaf-blindness, deafness, hearing impairments, mental impairments, multiple disabilities, orthopedic impairments, other health impairments, emotional handicaps, learning disabilities, communication disorders, traumatic brain injury, and visual impairments.

DOH or ISDH

Department of Health or Indiana State Department of Health (<http://www.in.gov/isdh/index.htm>) agency which serves to promote, protect, and provide for the public health of people in Indiana.

DOI

Department of Insurance (<http://www.in.gov/idoi/>)- agency which enforces statutes and regulations applicable to the operation of approximately 1,780 insurance companies, the issuance of insurance policies, the handling of complaints, and the dissemination of public insurance information. The Department, headed by a commissioner appointed by the governor, employs approximately 80 persons.

Deinstitutionalization

Policy which describes the provision of supportive care and treatment for medically and socially dependent individuals in the community rather than in an institutional setting.

Disability

Any limitation of physical, mental or social activity of an individual as compared with other individuals of similar age, sex, and occupation. Frequently refers to limitation of a person's usual major activities, most commonly vocation. There are varying types (functional, vocational, learning), degrees (partial, total), and durations (temporary, permanent) of disability. Public programs often provide benefits for specific disabilities, such as total and permanent.

Dually Diagnosed

Dual Diagnosis is a term applied to the co-existence of the symptoms of both mental retardation and mental illness.

Endangered Adult

Individuals who are at least 18 years of age, incapable of caring for themselves, and being abused, neglected, or exploited.

FSSA

The Family and Social Services Administration (<http://www.in.gov/fssa/>)- an agency of the State of Indiana providing services to families who have issues associated with:

- low income,
- mental illness,
- addiction,
- mental retardation,
- a disability,
- aging, and
- children who are at risk for healthy development.

First Steps

A coordinated system of statewide local interagency councils whose mission it is to assure that all Indiana families with infants and toddlers experiencing developmental delays or disabilities have access to early intervention services close to home when they need them.

Group Home

A Group Home is a residential facility for a group that requires special care or supervision, such as children, mentally ill, senior citizens, or troubled teens or persons.

Health Professions Bureau

(<http://www.in.gov/hpb/>) Provides professional, quality support services to Indiana's health regulatory boards and committees, in furtherance of their responsibility to assure the safe and competent delivery of health care to the citizens of Indiana.

Healthy Families

A voluntary home visitation program designed to promote healthy families and healthy children through a variety of services, including child development, access to health care, and parent education.

Home Health Care Agency

A home health care agency is a public or private agency that specializes in giving skilled nursing services, home health aides, and other therapeutic services, such as physical therapy, in the home.

Home Health Care

Health care services provided in the home on a part time basis for the treatment of an illness or injury. Medicare pays for home health care only if the type of care needed is skilled and required on an intermittent or part-time basis, and is intended to help people recover or improve from an illness or injury.

Hoosier Healthwise

A health insurance program for Indiana children, pregnant women, and low-income families. Health care is provided at little or no cost to Indiana families enrolled in the program.

HoosierRx

Indiana's prescription drug program for low-income seniors. Any eligible senior enrolled in the HoosierRx Program will receive 50% of the cost of their medications, up to a yearly benefit cap.

ICF/MR

Intermediate Care Facility for the Mentally Retarded— A facility in which individuals with developmental disabilities live together. There is 24-hour supervision by paid staff who provide assistance and training to help residents develop daily living skills, with programming for each individual's needs. These residences may be large, state or privately operated facilities, or group homes for 4 to 8 residents.

IDOL

Indiana Department of Labor (<http://www.in.gov/labor/>)— agency seeks to promote the welfare of Indiana's workforce by administering a variety of educational and compliance programs designed to provide the knowledge and tools necessary to guarantee workers' rights to safe, healthful, positive work environments, and the appropriate compensation for that work.

IHFA

Indiana Housing Finance Authority (<http://www.in.gov/ihfa/>)— created in 1978 by the Indiana General Assembly, it is a state-operated bank that finances residential mortgages and the development of rental housing. In addition, it is also a community development organization. IHFA provides affordable homes for Hoosiers, stimulates the construction industry and construction employment, and is financially self-sufficient. No state taxes are used for operating support of IHFA.

IHSS

In-Home Supportive Services —Non-medical services to help functionally impaired persons of all ages, with limited resources, stay at home. (For those who qualify, it is paid by Title XX of the Social Security Act.)

IMPACT

The Indiana Manpower & Comprehensive Training service— Provides job-related services to help TANF and Food Stamp recipients become economically self-sufficient.

INDOT

Indiana Department of Transportation (<http://www.in.gov/dot/>)— the agency's mission is to provide our customers the best transportation system that enhances mobility, stimulates economic growth, and integrates safety, efficiency and environmental sensitivity.

Independent Living Services

Promotes a philosophy of independent living including consumer control, peer support, self help, self determination, equal access, and individual and system advocacy, to maximize the integration and full inclusion of individuals with disabilities, community leadership, empowerment, independence, and productivity.

Institutionalization

Admission of an individual to an institution, such as a nursing home, for an extended period of time or indefinitely.

Intermediary or Fiscal Intermediary

An organization that handles Part A (*see definition*) claims submitted by hospitals, skilled nursing facilities, home health agencies, hospices, and other providers of services.

Intermittent Care

Not daily care, but care done on a part time basis.

IPAS

Indiana Protection and Advocacy Services (<http://www.in.gov/ipas/>)- Mission is "to protect and promote the rights of individuals with disabilities, through empowerment and advocacy."

- May be able to assist citizens of Indiana who have a disability and are either being denied a right or are being discriminated against because of that disability.
- Administers 6 Federally Mandated and Funded Programs for Indiana
 - Client Assistance Program (CAP)
 - Protection and Advocacy for Assistive Technology (PAAT)
 - Protection and Advocacy for Beneficiaries of Social Security (PABSS)
 - Protection and Advocacy for Individuals with Developmental Disabilities (PADD)
 - Protection and Advocacy for Individuals with Mental Illness (PAIMI)
 - Protection and Advocacy for Individual Rights (PAIR)
- Is an Independent State Agency which receives no state funding and is Independent from all service providers.
- As required by federal law and state law, must be and is independent of state governmental control.
- Is governed by the 13-member [IPAS Commission](#) which sets the agency's [Priorities](#).
- Is advised on Mental Illness matters by a 10-member [Advisory Council \(MIAC\)](#).

Kids at Risk

Children who are "at risk" of failing to succeed in life because of the adversities of their young lives. Poverty, family discord, violence and abuse, substance abuse, and illness are among the hazards.

Lifetime Reserve Days

Sixty extra days provided by Medicare hospital insurance (Part A) that can be used in case of a long illness where the stay in the hospital is more than 90 days. Reserve days are not renewable – they can only be used once. A co-payment is required.

Long Term Care Insurance

A policy designed to help alleviate some of the costs associated with long term care, such as nursing home or home health care costs.

LTC

Long Term Care – the medical and social care given to individuals with impairments covering a long period of time. Long term care can consist of care in the home by family members, assisted with voluntary or employed help (such as provided by home healthcare agencies), adult day care, or care in institutions.

Medicaid

A federal-state partnership designed to ensure that the United States' aged, sick, and impoverished are cared for. This program, authorized by Title XIX of the Social Security Act, is a safety net that provides aid in the form of medical services to people who fall below the state-established poverty line. Subject to broad federal guidelines, states determine the benefits covered, program eligibility, rates of payment for providers, and methods for administering the program.

Medically Necessary

Medical necessity must be established (through diagnostic and/or other information presented on the claim under consideration) before Medicare or the insurance company will make payment

Medically Needy

Persons who are categorically eligible for Medicaid and whose income, less accumulated medical bills, is below state income limits for the Medicaid program (see Spend Down).

Medicare Part A

This provides either total or partial coverage for hospital care, skilled nursing facility care, home health care services, and hospice services.

Medicare Part B

This covers a portion of the costs for doctors' care; physical, occupational and speech therapy sessions; ambulance services; prostheses; medical equipment; and home health services.

M.E.D. Works

Medicaid for Employees with Disabilities- allows disabled working individuals with incomes too high for regular Medicaid to be eligible for health coverage. M.E.D. Works members whose income is more than 150% of the federal poverty level will be charged a premium on a sliding-fee scale based on income. These individuals will receive the full-range of traditional Medicaid-covered services and will pay the same co-payments for certain services. This law was passed by the Indiana Legislature in 2001.

MI

Mental Illness - Mental illnesses are disorders of the brain that disrupt a person's thinking, feeling, moods, and ability to relate to others. Mental illnesses are disorders of the brain that often result in a diminished capacity for coping with the ordinary demands of life.

MR

Mentally Retarded – This is a disorder in which a person's overall intellectual functioning is well below average, with an intelligence quotient (IQ) around 70 or less. Individuals with mental retardation also have a significantly impaired ability to cope with common life demands and lack some daily living skills expected of people in their age group and culture. The impairment may interfere with learning, communication, self-care, independent living, social interaction, play, work, and safety. Mental retardation appears in childhood, before age 18 and affects approximately 1-2% of the population.

Nursing Home

A place where persons reside who need some level of medical assistance and/or assistance with activities of daily living. Not all nursing homes are Medicare or Medicaid approved/certified facilities.

Nursing Home Policy

Type of health insurance policy which generally pays indemnity benefits for medically necessary stays in nursing homes (sometimes referred to as Long Term Care policies).

OAA

Older Americans Act – Federal legislation enacted in 1965 to provide money for programs and direction for a multitude of services designed to enrich the lives of senior citizens. Example adequate housing, income, employment, nutrition, and health care.

OBRA

Omnibus Budget Reconciliation Act

Occupational Therapy

Therapy by means of work (i.e., arts and crafts) designed to divert the mind, to correct a particular physical defect, or to equip a handicapped patient with new skills.

OMPP

Office of Medicaid Policy and Planning— part of the Family and Social Services Administration. Determines level of care of Intermediate Care Facilities for the Mentally Retarded (ICF/MR), waivers, and nursing homes. It is responsible to CMS for oversight of the Medicaid waiver program.

Olmstead Decision

The Olmstead decision issued in 1999 interpreted Title II of the Americans with Disabilities Act (ADA) and its implementing regulation, requiring States to administer their services, programs, and activities "in the most integrated setting appropriate to the needs of qualified individuals with disabilities." Medicaid is the main resource in helping states to meet these goals. However, the scope of the ADA and the Olmstead decision are not limited to Medicaid beneficiaries or to services financed by the Medicaid program. The ADA and the Olmstead decision apply to all qualified individuals with disabilities regardless of age

Ombudsman

A "citizens' representative" who protects a person's rights through advocacy, providing information, and encouraging institutions or agencies to respect citizens' rights. Two programs: DD Ombudsman and Aging Ombudsman.

Per Diem

Per day, or a daily charge.

Personal Care

Assistance provided to people who need help with bathing, cooking, dressing, eating, grooming or personal hygiene. These service are not routinely paid for by either Medicare or Medicaid, but for those who qualify may be paid for by IHSS.

PPS

Prospective Payment System – Under PPS, nursing facilities are paid fixed amounts based on the Resource Utilization Group (RUG) for the person based on their relative staff and resource needed and acuity. In some cases, the Medicare payment will be more than the actual cost of providing services for that stay. In other cases, the payment will be less than the nursing facility's actual cost.

Provider

A generic term describing any individual, organization or company enrolled to provide services. Qualifications vary depending on the type of service provided.

Psychiatric Hospital Care

Medicare Part A can help pay for no more than 190 days of care in your lifetime in a participating psychiatric hospital.

Reasonable and Necessary Care

The amount and type of health services generally accepted by the health community as being required for the treatment of a specific disease or illness.

Rehabilitation

The coordinated use of medical, social, educational, and vocational measures for training or retraining individuals disabled by disease or injury to the highest possible level of functional

ability. Several different types of rehabilitation are distinguished: vocational, social, psychological, medical and educational.

RCAP

Residential Care Assistance Programs- State program that pays for care provided in licensed residential care facilities (assisted living) and in county homes for low income persons needing this level of care.

Respite Care

Short term care given to a person(s) with an illness or disability in the home, nursing home, or hospital; intended to give relief to the principal caretakers.

Sheltered Workshop

A segregated setting in which persons with disabilities who are not capable, temporarily or permanently, of competitive employment in the community are provided with vocational, pre-vocational, and habilitative services and experience.

Skilled Nursing Care

Care which can only be provided by or under the supervision of licensed nursing personnel.

Skilled Nursing Facility

A Medicare participating nursing facility which is staffed and equipped to furnish skilled nursing care, skilled rehabilitation services, and other related health services for which Medicare pays benefits.

Social Security Administration

This federal agency is responsible for the Medicare enrollment process, for determining Medicare eligibility, and for SSI and SSDI benefits.

Social Security Benefits

Benefits payable under Social Security programs, can be assigned to three general categories – retirement benefits, survivor benefits, and disability benefits.

Spend Down

1) A process of becoming eligible for Medicaid nursing home assistance by exhausting one's assets to pay for their care, until Medicaid asset eligibility is established. 2) A process of becoming eligible for Medicaid at home **or nursing home** assistance by paying for medical care out of one's own income, until Medicaid income eligibility is established. This occurs on a monthly basis, after asset eligibility is met on the 1st day of the month.

Spousal Impoverishment Provision

The community property and assets of a nursing home resident who is married may be divided to protect the property and assets of the spouse not in the nursing home.

State Budget Agency

(<http://www.in.gov/sba/agencyinfo/>)- the agency's mission is to achieve excellence in fiscal decision making and fiscal results on behalf of the Governor and in support of the General Assembly. The State Budget Agency facilitates the processes of revenue forecasting, budget development, and budget implementation. The Budget Agency evaluates and communicates the fiscal and policy impacts of legislative proposals with the objective of assuring best information available to decision makers.

State Fiscal Year

The state fiscal year for the state of Indiana begins on July 1st and ends on June 30th of the next year.

Supported Employment

Individuals with the most severe disabilities are placed in competitive jobs with qualified job coaches/trainers to provide individualized, ongoing support services needed for each individual to retain employment. The employee is contacted monthly, either at or away from the workplace, to address any issues that may threaten the individual's ability to remain on the job.

Ticket to Work

The Ticket to Work and Work Incentives Improvement Act of 1999 provides States with three opportunities to assist disabled persons to maintain employment: grants to States to develop the administrative and internal structures in their Medicaid programs necessary to support people with disabilities who are employed; a demonstration to provide health care benefits to employed individuals with potentially disabling conditions; and two new opportunities to use federal matching funds for providing Medicaid benefits to working disabled.

Title XVIII

The portion of the Social Security Act which clearly defines the provisions of Medicare.

Title XIX

The portion of the Social Security Act which clearly defines the provisions of Medicaid.

Vocational Rehabilitation

Provides comprehensive, coordinated, effective, efficient, and accountable services needed by eligible individuals with disabilities to prepare for, enter, engage in, and retain employment consistent with each individual's strengths, resources, priorities, concerns, abilities, capabilities, and informed choice.

VRS

Vocational Rehabilitation Services- Vocational Rehabilitation Services (VRS) assists eligible people with disabilities to achieve employment and independence. VRS is committed to securing quality individualized services which enable individuals with disabilities, including individuals with the most severe disabilities, to pursue meaningful careers by obtaining gainful employment consistent with their abilities and capabilities.

VRS customers have the responsibility to participate in their own rehabilitation program, including making meaningful and informed choices about the selection of the employment outcome, vocational objectives, and vocational rehabilitation providers. Each VRS customer works in partnership with his or her vocational rehabilitation counselor who provides on-going rehabilitation counseling, case management, and follow up through each phase of the process of vocational rehabilitation.

To be eligible to participate in the VRS program, an individual must have a physical or mental disability, which results in a substantial impediment to employment, and the individual must require services to prepare for, enter into, engage in, or retain gainful employment. Services provided by VRS must be directly linked to an employment outcome, and must be necessary for an individual to perform the basic duties of a job.

Waiver

The Medicaid Waiver programs are funded with both State and Federal dollars. All waiver programs have been initiated by the Indiana General Assembly and approved by the CMS. Eligibility for all waiver programs requires:

- The recipient must meet Medicaid guidelines.
- The recipient would require institutionalization in the absence of the waiver and/or other home-based services.
- The total aggregate Medicaid cost of serving the recipient(s) on the waiver (waiver cost plus other Medicaid services), cannot exceed the total aggregate cost to Medicaid for serving the recipient (s) in an appropriate institutional setting(s).

Current Indiana Waivers include:

Governor's Commission on Home and Community Based Services
Data Book

- Aged and Disabled Waiver
- Autism Waiver
- DD Waiver
- Medically Fragile Children's Waiver
- Traumatic Brain Injury Waiver
- Assisted Living Waiver
- Support Services Waiver

Work One

Work One Centers are places that assist customers in finding workers or finding jobs. Partnering agencies are able to share information about customers that gives the Center a "single agency" appearance (although customers that want to work with a single agency can restrict information to that agency).

SECTION VI: OTHER RESOURCES

The Indiana Governor's Planning Council
<http://www.in.gov/gpcpd/>

Administration on Aging, Department of Health and Human Services
<http://www.aoa.dhhs.gov/>

**National Information Center for
Children and Youth with Disabilities**
<http://nichcy.org/index.html#about>

State Agencies and Organizations

United States Senators

Honorable Richard G. Lugar (R)
United States Senate
306 Hart Senate Office Building
Washington, DC 20510-1401
(202) 224-4814
E-mail: senator_lugar@lugar.senate.gov
Web: www.senate.gov/~lugar/

Honorable Evan Bayh (D)
United States Senate
717 Hart Building
Washington, DC 20510
(202) 224-5623
(202) 228-1377 (fax)
Web: www.senate.gov/~bayh/

Governor

Honorable Frank O'Bannon
State House, Room 206
Indianapolis, IN 46204
(317) 232-4567
E-mail: fobannon@state.in.us
Web: www.ai.org/gov/index.html

State Department of Education: Special Education

Robert Marra, Associate Superintendent
Indiana Department of Education
State House, Room 229
Indianapolis, IN 46204-2798
(317) 232-0570
E-mail: rmarra@doe.state.in.us
Web: <http://web.indstate.edu/soe/iseas/dse.html>

Programs for Infants and Toddlers with Disabilities: Ages Birth through 2

J. Lanier DeGrella, Assistant Deputy Director
Indiana Family and Social Services Administration
Division of Family and Children
Bureau of Child Development
402 W. Washington Street, Room W-386
Indianapolis, IN 46204
(317) 233-9229

E-mail: jdegrella@fssa.state.in.us

Web: www.in.gov/fssa/first_step/

Programs for Children with Disabilities: Ages 3 through 5

Sheron Cochran, Preschool Coordinator

Division of Exceptional Learners

Indiana Department of Education

State House, Room 229

Indianapolis, IN 46204-2798

(317) 232-0567

E-mail: scochran@doe.state.in.us

Web: <http://web.indstate.edu/soe/iseas/dse.html>

State Vocational Rehabilitation Agency

Nancy Zemaitis, Interim Deputy Director

Vocational Rehabilitation Services

Indiana Family and Social Services Administration

Division of Disability, Aging, and Rehabilitative Services

402 W. Washington Street, Room W453

P.O. Box 7083

Indianapolis, IN 46207-7083

(317) 232-1319; (800) 545-7763, ext. 1319

E-mail: nzemaitis@fssa.state.in.us

Web: www.IN.gov/fssa/

Office of State Coordinator of Vocational Education for Students with Disabilities

Terry Fields, State Director

Vocational and Technical Education

Indiana Workforce Development

10 N. Senate Avenue, Room 212

Indianapolis, IN 46204-2277

(317) 232-1829

E-mail: tfields@dwd.state.in.us

Web: www.IN.gov/dwd/teched/

State Mental Health Agency

Janet Corson, Director

Division of Mental Health and Addiction

Family and Social Services Administration

402 W. Washington Street, Room W353

Indianapolis, IN 46204-2739

(317) 232-7845

E-mail: jcorson@fssa.state.in.us

Web: www.IN.gov/fssa

State Mental Health Representative for Children

Children's Services Bureau

Division of Mental Health and Addiction

Family and Social Services Administration

402 W. Washington Street, Room W353

Indianapolis, IN 46204-2739

(317) 232-7934

Web: www.IN.gov/fssa

State Developmental Disabilities Agency

Steven C. Cook, Director

Bureau of Developmental Disabilities

Governor's Commission on Home and Community Based Services
Data Book

Indiana Family and Social Services Administration
Division of Disability, Aging, and Rehabilitative Services
P.O. Box 7083
Indianapolis, IN 46207-7083
(317) 232-7842

State Developmental Disabilities Planning Council

Suellen Jackson-Boner, Director
Governor's Planning Council for People with Disabilities
150 W. Market Street, Suite 628
Indianapolis, IN 46204
(317) 232-7770; (317) 232-7771 (TTY)
E-mail: gpcpd@gpcpd.org
Web: www.IN.gov/gpcpd

Protection and Advocacy Agency

Thomas Gallagher, Executive Director
Indiana Protection and Advocacy Services
4701 N. Keystone Avenue, Suite 222
Indianapolis, IN 46205
(317) 722-5555
(800) 622-4845; (800) 838-1131 (TTY)
E-mail: info@ipas.state.in.us
Web: www.IN.gov/ipas

Client Assistance Program

Contact Protection and Advocacy Agency listed above

Programs for Children with Special Health Care Needs

Children's Special Health Care Services
Indiana State Department of Health
2 N. Meridian Street, Section 7-B
Indianapolis, IN 46204
(317) 233-5578

State Agency for the Blind and Visually Impaired

Linda Quarles, Interim Deputy Director
Blind and Visually Impaired Services
Indiana Family and Social Services Administration
Division of Disability, Aging, and Rehabilitative Services
402 W. Washington Street, Room W-453
P. O. Box 7083
Indianapolis, IN 46207-7083
(317) 232-1433; (877) 241-8144
(317) 232-1466 (TTY)
E-mail: lquarles@fssa.state.in.us
Web: www.state.in.us/fssa/servicedisabl/blind/index.html

Programs for Children and Youth who are Deaf or Hard of Hearing

James Van Manen, Deputy Director
Deaf and Hard of Hearing Services
Indiana Family and Social Services Administration
Division of Disability, Aging, and Rehabilitative Services
402 W. Washington Street, Room W-453
P.O. Box 7083
Indianapolis, IN 46207-7083
(317) 232-1143 (V/TTY); (800) 962-8408 (V/TTY in IN only)

E-mail: jvanmanen@fssa.state.in.us
Web: www.IN.gov/fssa/dhhs

Regional ADA Technical Assistance Agency

Robin Jones, Project Director
Great Lakes Disability and Business Technical Assistance Center
University of Illinois/Chicago
Department on Disability and Human Development
1640 W. Roosevelt Road
Chicago, IL 60608
(312) 413-1407 (V/TTY); (800) 949-4232 (V/TTY)
E-mail: gldbtac@uic.edu
Web: www.adagreatlakes.org

University Centers for Excellence on Developmental Disabilities

(formerly University Affiliated Programs)
David M. Mank, Director
Indiana Institute on Disability and Community
2853 E. Tenth Street
Bloomington, IN 47408-2696
(812) 855-6508; (812) 855-9396 (TTY)
E-mail: uap@indiana.edu
Web: www.iidc.indiana.edu

John D. Rau, M.D., Director
Riley Child Development Center (RCDC)
Leadership Education in Neurodevelopmental Disabilities (LEND) Program
Indiana University School of Medicine
James Whitcomb Riley Hospital for Children
702 Barnhill Drive, Room 5837
Indianapolis, IN 46202-5225
(317) 274-8167
E-mail: jdrau@child-dev.com
Web: www.child-dev.com

Technology-Related Assistance

Cris Fulford, Executive Director
ATTAIN, Inc.
2346 S. Lynhurst Drive, Suite 507
Indianapolis, IN 46241
(317) 486-8808; (800) 528-8246 (in IN)
E-mail: attain@attaininc.org
Web: www.attaininc.org

State Mediation System

Sally Cook, Coordinator
Indiana Department of Education
Division of Exceptional Learners
State House, Room 229
Indianapolis, IN 46204
(317) 232-0580
E-mail: sacook@doe.state.in.us
Web: web.indstate.edu/soe/iseas/dse.html

Disability-Specific Organizations

Attention Deficit Disorder

To identify an ADD group in your state or locality, contact either:

Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD)

8181 Professional Place, Suite 201

Landover, MD 20785

(301) 306-7070

(800) 233-4050 (Voice mail to request information packet)

E-mail: national@chadd.org

Web: www.chadd.org

National Attention Deficit Disorder Association (ADDA)

1788 Second Street, Suite 200

Highland Park, IL 60035

(847) 432-2332

E-mail: mail@add.org

Web: www.add.org

Autism

Cathy Pratt, Ph.D., Director

Indiana Resource Center for Autism (IRCA)

Indiana Institute on Disability and Community

2853 E. Tenth Street

Bloomington, IN 47408-2696

(812) 855-6508; (812) 855-9396 (TTY)

E-mail: prattc@indiana.edu

Web: www.iidc.indiana.edu/

Brain Injury

John P. Young, Chairman, Board of Directors

Brain Injury Association of Indiana

1525 N. Ritter Avenue, Mikolon Building

Indianapolis, IN 46219

(317) 356-7722; (866) 854-4246

E-mail: BIAl@iquest.net

Web: www.biausa.org/indiana/bia.htm

Cerebral Palsy

Donna Roberts, Executive Director

United Cerebral Palsy Association of Greater Indiana, Inc.

615 N. Alabama Street, Room 322

Indianapolis, IN 46204

(317) 632-3561; (800) 723-7620

E-mail: ucpaindy@ucpaindy.org

Down Syndrome

Indiana Down Syndrome Foundation

233 McCrea Street, Suite 200

Indianapolis, IN 46225

(317) 216-6319; (888) 989-9255

E-mail: dsani@aol.com

Web: www.indianadsf.org

Deb Gavette, President

Down Syndrome Association of Northeast Indiana

P.O. Box 50305

Fort Wayne, IN 46815

(260) 471-9964; (877) 713-7264

E-mail: dsani4u@aol.com

Web: www.dsani.org

Epilepsy

Marge Frommeyer, Executive Director
Epilepsy Council of Greater Cincinnati, Inc.
(serving Clark, Floyd and South Eastern Counties)
3 Centennial Plaza, 895 Central Avenue
Cincinnati, OH 45202
(513) 721-2905
E-mail: ecgc@fuse.net
Web: www.ecgc.net

Learning Disabilities

Dawn Lytle, Indiana State President
Learning Disabilities Association of Indiana
P.O. Box 20584
Indianapolis, IN 46220
(800) 284-2519 (LD and ADD/HD Information Request Line)
E-mail: dlytle@kokomo.k12.in.us
Web: www.lidaamerica.org

Mental Health

Stephen McCaffrey, President
Mental Health Association in Indiana, Inc.
55 Monument Circle, Suite 455
Indianapolis, IN 46204
(317) 638-3501; (800) 555-6424 (in IN only)
E-mail: mha@mentalhealthassociation.com
Web: www.mentalhealthassociation.com

Pamela A. McConey, Executive Director
NAMI Indiana (National Alliance for the Mentally Ill, IN)
P.O. Box 22697
Indianapolis, IN 46222-0697
(317) 925-9399; (800) 677-6442
E-mail: nami-in@nami.org
Web: www.namiindiana.org

Mental Retardation

John Dickerson, Executive Director
The Arc of Indiana
22 E. Washington Street, Suite 210
Indianapolis, IN 46204
(317) 977-2375
E-mail: jdickerson@iquest.net
Web: www.arcind.org
Web: www.TheArcLink.org

Speech and Hearing

Michael Flahive, President
Indiana Speech-Language-Hearing Association
233 McCrear Street, Suite 200
Indianapolis, IN 46225
(317) 955-1063
E-mail: isha@in-motion.net

Web: www.islha.org

Spina Bifida

Spina Bifida Association of Northern Indiana
2421-01 Nappanee Street
Elkhart, IN 46517
(574) 295-3988; (866) 822-6499

Kim Zink, Coordinator
Wabash Valley Spina Bifida Support Group
P.O. Box 21
Farmersburg, IN 47850
(812) 696-2288
E-mail: spinabifida@earthlink.net
Web: www.homestead.com/planetzachary/main.html

Visual Impairments

Jay Stiteley, Director
American Foundation for the Blind-Midwest
401 N. Michigan Avenue, Suite 350
Chicago, IL 60611
(312) 396-4420
E-mail: chicago@afb.net
Web: www.afb.org

Organizations Especially for Parents

Parent Training and Information Center (PTI)

Richard Burden, Executive Director
IN*SOURCE
809 N. Michigan Street
South Bend, IN 46601-1036
(219) 234-7101 (V/TTY); (219) 239-7575 (TTY)
(800) 332-4433 (In IN)
E-mail: insource@insource.org
Web: www.insource.org

Parent-To-Parent

Donna Gore Olsen, Executive Director
Indiana Parent Information Network, Inc.
4755 Kingsway Drive, Suite 105-A
Indianapolis, IN 46205-1545
(317) 257-8683
E-mail: FamilyNetw@aol.com
Web: www.ai.org/ipin

Parent Teacher Association (PTA)

Mary Williams, President
Indiana Congress of Parents and Teachers, Inc.
2525 N. Shadeland Avenue, D-4
Indianapolis, IN 46219
(317) 357-5881
E-mail: in_office@pta.org
E-mail: pta@spitfire.net
Web: www.indianapta.org

Other Disability Organizations

Pat Bowers, Executive Director
Easter Seals Wayne/Union Counties
5632 U.S. Highway 40 East
P.O. Box 86
Centerville, IN 47330-0086
(765) 855-2482
E-mail: easterseals@juno.com

Jim Nulty, President
VSA arts of Indiana
Harrison Centre for the Arts
1505 N. Delaware Avenue
Indianapolis, IN 46202
(317) 974-4123; (317) 974-4117 (TTY)
E-mail: jnulty@vsai.org
Web: www.vsai.org

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